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ABSTRACT

The report documents the progress and accomplishments of the SEFAM (Supporting Extended Family Members) Program, which developed model programs for fathers, siblings, and grandparents. The first section summarizes staff efforts for five project objectives: (1) to develop, expand, test, and refine the pilot "Fathers and Infants/Toddlers" program to encompass fathers, siblings, and other members of handicapped young children's extended families in a replicable model program; (2) to coordinate model planning and development with personnel from the state education agency, public schools, community service organizations, and professionals from other disciplines; (3) to design and field test a curriculum using strategies for increasing family members' skills in coping with, interacting with, and educating their child with special needs, and in fostering a nurturing environment; (4) to develop field test, and refine products concerning the evolving and final model (including curriculum materials and assessment procedures); and (5) to disseminate information on the model to professional, governmental, and general audiences and to make available product materials and products. Extensive appended information (in Appendix A, the bulk of the document) includes "Supporting Fathers of Handicapped Young Children: Preliminary Findings of Program Effects" (P. F. Vadasy, et al.), "Fathers of Children with Handicaps: Developmental Trends in Fathers' Experiences over the Family Life Cycle" (D. J. Meyer), "Supports from Religious Organizations and Personal Beliefs" (R. R. Fewell), and "They Became a Substitute Family" (C. T. Moeller), the Father's Program on 32 fathers of handicapped children and a paper on developmental trends in fathers' experiences over the family life cycle. (CL)

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ED254992

FINAL REPORT

Supporting Extended Family Members (SEFAM) Program
An HCEEP Demonstration Project

Grant # G008100080
Project # 024AH30009

August 1, 1981 - October 30, 1984

Experimental Education Unit
Child Development and Mental Retardation Center
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Seattle, Washington 98195

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Submitted January 11, 1984

EC 172044

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SEFAM Final Report

Introduction and Overview

In 1978, staff and student volunteers at the University of Washington's Experimental Educational Unit established a pilot program for fathers and their handicapped infants and toddlers. At that time there were no programs in the Northwest region that specifically served fathers, and few programs in the country had made significant strides towards including fathers in their services. At that time, the needs and resources of fathers of children with handicaps were just beginning to be appreciated. In 1980, we applied for HCEEP demonstration support to develop and refine the pilot program so that it could be successfully replicated by agency staff in all parts of the country. The 3-year demonstration grant we received enabled us to continue our efforts to serve fathers, and to expand our efforts to serve two other groups of family members, siblings and grandparents, in the three components of the SEFAM (Supporting Extended Family Members) program.

In the first component under the grant, we developed a model program for fathers, one which is becoming locally and privately supported and self-sustaining here in Seattle, and one which we have taken opportunities to test and train others to replicate in several sites outside the region. We have also written a handbook for implementing the Father's Program model, which will be published in 1985. In the second component for siblings, we have developed a workshop format for serving young siblings, ages 8-13, addressing their needs for basic information and for peer support. With supplementary funding, we wrote a handbook for young siblings that is also being published in 1985. In the third component, we addressed the needs of grandparents in a workshop format that offered grandparents access to professional advice and mutual support from other grandparents. Our staff are continuing to work with this family group through our involvement with our local ARC which, with our assistance, has received a Parent Training grant to develop a group of programs for grandparents.

We are pleased to describe in this report how we have developed and refined, to varying degrees, three service models that address the specific needs of three family groups targeted in the component activities. Because in each year of our grant a new family group was phased in for services, the programs and products we developed represent varying degrees of effort and energy. Certainly the most highly developed SEFAM product is the Father's Program, upon which the grant was originally based. The original pilot program has been changed, somewhat, to reflect our careful examination of father's needs and how best to meet them. Program variations have been tested, both at the EEU demonstration site as well as in several other "pre-outreach" sites, and we have used our experiences to refine the basic model and to identify viable adaptations. These experiences are reflected in the written handbook we have prepared for those who wish to serve fathers. The Father's Program handbook provides an accessible rationale for the service model, and complete information on how to organize and present the program. The handbook will be distributed by the University of Washington Press, and will be available in early 1985.

As we will describe in more detail below, our program evaluation and related research efforts have focused primarily upon the fathers component of our services. Through the combined efforts of project staff and our consultant, Dr. Mark Greenberg, Professor of Psychology, and with supplementary funding, we designed a longitudinal followup study of the impact of program participation on fathers and their wives. We have disseminated in professional journals our preliminary findings on the positive effects of the program on both parents' stress and depression, making a contribution to the field in sorely needed data on the effects of programs for fathers.

Staff efforts at providing the bimonthly Father's Program and refining the program model spanned all 3 years of the project. Beginning in the second year and continuing through the third year, staff provided less frequent, but regular workshops for young siblings of children with handicaps. Each year, approximately four workshops were offered for young siblings ages 8-14. In somewhat the same way that we sought to supplement the longitudinal research in the Father's Program with additional research support, we successfully obtained support from the Department of Health and Human Services from October 1, 1982-September 30, 1983 to research, write, and fieldtest a handbook that would meet the special information and support needs of siblings of children with special needs. The handbook is an effective means of disseminating the information and experience we gained in our work with SEFAM siblings. The sibling handbook will be published by the University of Washington Press mid-1985. The sibling workshops are being continued at the EEU with local support, and staff have provided technical assistance to program staff in other parts of the country who wish to include siblings in their matrix of services.

In the final project year we added another series of workshops to serve grandparents, addressing their needs for information and support, and examining the nature of their experiences and interactions with the child's family through a questionnaire we developed. The continuation of this workshop program and spinoffs of an individual grandparent support program and a national grandparent newsletter are being made possible in 1984-85 by a Parent Training grant awarded to the King County Advocates for Retarded Citizens (ARC). SEFAM staff assisted the King County ARC to prepare the grant, and we will be consulting with their staff in each of the three program activities, the group workshops, the individual support program, and the newsletter.

Model development, implementation, and evaluation have been the priorities of the SEFAM demonstration program. SEFAM staff were concerned, from the initial planning of the grant, that the basic program evaluation provided for in traditional HCEEP demonstration projects would not adequately demonstrate the effects of making fathers the primary focus of a program's services. Child progress measures would not be appropriate, as children are not the target of services, but rather the child's entire family milieu, particularly the child's father, is the target audience. We recognized that the ecological scope of the project required an evaluation plan similarly broad in scope, and more rigorous in design than could be supported solely with demonstration funding. We have therefore supplemented the basic evaluation provided for in our HCEEP grant with research support from local sources, including the

Research Trust Fund of the Washington Association for Retarded Citizens, and the University's Graduate School Research Fund. With ongoing consultation from Dr. Mark Greenberg and from numerous visiting consultants to the program, we developed a comprehensive assessment battery that we administered annually to all fathers and their wives. Preliminary analyses of those longitudinal data indicate that parents who were involved in SEFAM's Father's Program reported less stress and depression, and more satisfaction with social supports than parents newly enlisted in the Program. These results are reported under Objective 1.0 below, and in publications attached in Appendix A.

The data we gathered on SEFAM parents raised several important questions that remain to be answered, including how these efforts maintain over time, and how the SEFAM parents differ from other parents of handicapped children who are not involved in a program for fathers. Continued followup and the addition of a control group needed to address these questions will be possible through a research grant we have obtained (Field-Initiated Research Study - FIRS), providing for a 3-year longitudinal study of participants and a group of matched controls. Like the three direct service components of SEFAM, the research we initiated during our HCEEP demonstration grant will continue at a refined and expanded level. Just as we are pleased to report that our efforts to serve family members have resulted in an array of innovative continuing programs that have attracted the support of local and private funding sources, we are equally pleased that the research we have initiated and refined during the past 3 years will continue beyond the end of this grant. Data on program impact are needed, not only to support the extension of the SEFAM Father's Program in other communities, but also to help us identify how we can make the model most responsive to families' needs.

As our readers will find, although this report marks the end of HCEEP demonstration funding, the SEFAM programs continue, some in expanded forms. The most important feature these legacies of SEFAM share, however, is their responsiveness to the family needs we have identified in our demonstration project. SEFAM was conceived and funded as an ecologically based approach to meeting the early needs of the young handicapped child through building a supportive family environment, the ecological system which is most influential in the young child's life. The services we have provided families and the models we have developed reflect that rationale. Our preliminary research supports the value of that approach, and we will continue to draw upon our experiences in SEFAM as we plan our future programs and studies of these special family systems.

Activities and Accomplishments in Meeting Project Objectives

This section of the report will summarize staff efforts over the past 3 years in regard to the objectives we identified for ourselves in our original grant application.

GOAL: TO PROVIDE AN ECOLOGICAL MODEL PROGRAM THAT ADDRESSES THE NEEDS OF TRADITIONALLY UNDERSERVED MEMBERS OF HANDICAPPED CHILDREN'S FAMILIES, WITH A VIEW TO PROVIDING THE CHILDREN WITH A FAMILY ENVIRONMENT THAT IS EDUCATIONALLY AND EMOTIONALLY SUPPORTIVE.

Objective 1.0 To further develop, expand, test, and refine the pilot Fathers and Infants/Toddlers Program established at the University of Washington in order to encompass fathers, siblings, and other members of handicapped young children's extended families in a replicable model program.

The SEFAM Program has included three major components: the original Father's Program, a program for siblings, and a program for grandparents. Our efforts in each year of the project expanded to include a new family group. In the first year, all of our work revolved around developing and refining the Father's Program so that the model could be replicated by others. In the second year, we added a program for siblings, and in the last year, a program for grandparents. The extent to which each program was refined was a function of the time we had to dedicate to them. The Father's Program is the major and most finished product of this grant. It represents 3 years of pilot work and 3 years of HCEEP-funded model development. It has undergone the most rigorous review and the most numerous changes. The greatest number of our written products and disseminables are associated with this component, including the Father's Program Handbook, reports of our research, grant proposals for supplementary and continued funding of the local service model and research, and other publications for both the professional and general audience.

The sibling program represents 2 years of staff efforts. Whereas the model for the Father's Program is a bimonthly program with a well-defined format, the sibling model is less intensive and more flexible. A workshop model was utilized to provide opportunities for young children to learn about handicaps, ask questions about matters of concern to them, share their experiences, and enjoy the company of other brothers and sisters of children with handicaps. With supplementary funding, we also prepared a written handbook that will be published in 1985 by the University of Washington press.

The grandparent program was the final component added to SEFAM in our last year of funding. Like the sibling component, it was based on a workshop model, and provided grandparents with several opportunities throughout the year to meet with professionals who could respond to their questions about their grandchild and family, and with other grandparents who could share peer support.

In our report on this objective, we will describe the major events in the development of these three components. Included in this section will be a description of the research we have initiated to evaluate the effects of our efforts.

Evolution of the Father's Program Model

At the time we submitted our original proposal, we described the format for the pilot program for fathers and infants we had developed. That format included opportunities for our staff to provide information to the participants, as well as opportunities for participants to explore and discuss their feelings. The model we have arrived at after 3 years of experience continues to provide those opportunities, but the manner in which the program is structured has been changed somewhat to facilitate those experiences. The fathers themselves have helped to shape the program through their feedback on program structure and content. We have surveyed participants to find out what they like and dislike about the program, and we have seriously considered their responses. For example, fathers' lukewarm responses to the "Zingers," or short controversial statements we originally used to stimulate discussions, were instrumental in our decision to drop these and use the time for more extended group discussion. The model has also evolved with help from many of the consultants who have visited the program and met with SEFAM staff. Dr. Harris Gabel, for example, observed the program in action and later critiqued tape recordings of group discussions in Father's Program meetings. The feedback he provided helped staff to refine their group discussion facilitation skills, as well as to consider changes in organization and scheduling that would encourage fathers to share their concerns.

Services Provided to Families

The demonstration program at the Experimental Education Unit has maintained a relatively stable enrollment of 20-30 families per year since the time of our pilot work on the program. An average of two-thirds of the children have Down syndrome, and the remaining children have handicaps including other syndromes, blindness, cerebral palsy, mental retardation, chromosome disorders, and undiagnosed developmental delays.

SEFAM's enrollment of children, and the demographic character of its families have been influenced by our immediate setting and more general Seattle location. We have had a large enrollment of children with Down syndrome due to our site, the Experimental Education Unit, where a widely known model program for serving these children was developed. The families who have participated in SEFAM have been primarily white and middle class, reflecting the demographic makeup of the Northwest region.

The Father's Program has provided twice monthly regular meetings, but several other services have also been available for families. Program staff Donald Meyer and Greg Schell, have consulted individually with fathers, as needed. We have also organized several annual all-family social occasions, under the auspices of the Father's Program. These have proven to be extremely important in themselves, in strengthening family mutual support networks. With supplementary funding from CEC in Year 2 we offered several workshops for fathers in the community, expanding our service base and addressing the needs of fathers who lived at too great a distance to participate regularly in the EEU program.

Evaluation of Program Impact

In our original grant, we wrote that our program evaluation efforts, like our service model, would be guided by an ecological rationale. With that goal in mind we immediately set out to plan as comprehensive an evaluation design as would be needed to capture the full range of program effects upon the child and family. Whereas most HCEEP demonstration projects target the handicapped child for services, the SEFAM Father's Program targeted the child's father for our intervention. It was the child's father whom we sought to involve and possibly influence in his attitudes and behaviors. Clearly, our assessment measures had to tap paternal domains that might change over the course of a father's involvement in our activities.

Guided by our ecological focus, we realized that changes in paternal domains might also produce changes in mother's domains, parental variables being so closely related. Hence, we included mothers in the scope of our assessments in order to determine whether our program has second-order effects on the wives of participating fathers.

Child progress, then, was not the primary outcome measure of concern to us as it is in most HCEEP demonstrations. It was not that we thought that we would have no impact on the child's development, but rather, that we knew we would have no means of determining to what degree our program contributed to child change. One of our service objectives was to identify appropriate educational placements for all children who were not already enrolled in a program when their fathers entered SEFAM; hence any measure of child progress would reflect, to a large degee, the child's participation in his/her primary education program, with SEFAM involvement being a lesser contributing factor.

At the outset of the project we worked with our consultant, Dr. Mark Greenberg, whose services were made possible through technical assistance from TADS, to identify the family measures we would administer. Our research design was a one-group pretest-posttest design, determined largely by pragmatic considerations. Random assignment was impossible for ethical reasons, and resources were unavailable for the use of a control group. We identified family domains that we hypothesized would be influenced by fathers' involvement in the program, and weighed the merits and disadvantages of available instruments. The matrix displayed in Table 1 describes the assessment battery we administered to parents pre and post Year 1. We hoped that after we reviewed the results of the 10 measures at the end of Year 1 we would be able to identify a smaller set of measures, showing some variance between parents that would reflect the length of their involvement in the program. Within the Year 1 sample, we tested parents who had been involved in the pilot program from 1-3 years, and we compared the pretest data of those pilot parents (n=7) to the group of newly entering parents (n=16). We found that fathers in the pilot program differed from newly enrolled fathers in several areas (see Tables 1 and 2): they reported lower depression levels ($p < .01$), lower levels of sadness ($p < .001$), higher feelings of success as a person ($p < .05$), less guilt ($p = .01$), better decision-making skills ($p < .05$) and less fatigue ($p < .05$). The fathers in the pilot program also differed in their reports of satisfaction with social supports compared to newly enrolled fathers: they reported greater satisfaction with neighborhood

Table 1

Means*, Standard Deviations, and
Significance of Paternal Dependent Variables by
Father Participation (Analyses of Covariance)

	Program Fathers		New Fathers		F ratio
Dependent Measure	Mean	S.D.	Mean	S.D.	(1,14)
Beck Depression Inventory					
Total Score	2.20	2.8	7.19	5.2	9.4, $p < .01$
Sadness	0.00	0.0	0.52	0.6	15.5, $p < .001$
Fatigue	0.20	0.5	0.83	0.6	6.9, $p < .05$
Satisfaction	0.02	0.4	0.80	0.6	7.0, $p < .05$
Future Concerns	0.05	0.5	0.68	0.6	4.9, $p < .05$
Success/Failure	0.00	0.0	0.35	0.5	6.5, $p < .05$
Guilt	0.04	0.1	0.55	0.8	7.7, $p = .01$
Decision-Making	0.17	0.4	0.58	0.6	5.3, $p < .05$
Inventory of Parent Experiences					
Sharing Happy Events	4.01	0.5	2.79	0.8	5.0, $p < .05$
Sharing Private Feelings	4.17	0.8	2.65	1.0	5.6, $p < .05$
Religious Satisfaction	4.33	0.5	3.03	0.8	4.5, $p < .05$
Neighborhood Satisfaction	4.02	0.8	2.70	0.9	4.1, $p = .06$
QRS-F					
Child's Incapacitation[a]	4.16	0.9	5.71	1.0	4.5, $p = .05$
Total Problems[b]	0.86	3.9	6.51	3.4	7.9, $p = .01$

* All means are adjusted for the covariates of child's age, father's education, and father's occupational status

[a] Child's chronological age was significant covariate ($p < .05$)

[b] Father's education ($p < .05$) and occupation ($p < .05$) were significant covariates

Table 2

Means*, Standard Deviations, and Significance of Maternal Dependent Variables by Father Participation (Analyses of Covariance)

	Wives of Program Fathers		Wives of New Fathers		
Dependent Measure	Mean	S.D.	Mean	S.D.	F ratio (1,19)
Beck Depression Inventory					
Success/Failure	0.00	0.0	0.30	0.6	4.3, $p = .05$
Appearance/ Attractiveness	0.04	0.4	0.74	0.8	3.6[b], $p < .10$
Inventory of Parent Experiences					
Sharing Happy Events	4.01	0.5	2.79	0.8	5.0, $p < .05$
Satisfaction Time to Self	3.74	1.0	2.45	0.9	3.4[c], $p < .08$
Family Environment Scale					
Family Expressiveness	3.30	1.3	2.42	0.8	3.2, $p < .10$
Family Independence	3.31	0.8	2.48	0.9	3.2, $p < .10$
QRS-F					
Child's Characteristics	5.67	2.0	7.83	2.1	3.7[a], $p = .08$

* All means are adjusted for the covariates of maternal education and child's age. No significant effects were found for the covariates.

[a] df (1,15)

[b] df (1,18)

[c] df (1,19)

supports ($p = .06$), greater religious satisfaction ($p < .05$), and greater satisfaction sharing happy events and private feelings ($p < .05$).

Our analysis of data from our first assessment of families also revealed that fathers' participation had second-order effects on the fathers' wives, who differed from wives of newly enrolled fathers in the following areas: higher reports of success ($p = .05$) and personal attractiveness ($p < .10$); greater satisfaction sharing happy events ($p < .05$) and greater satisfaction with the amount of personal time available to them ($p < .08$); higher levels of family independence and expressiveness ($p < .10$); and less stress due to their child's characteristics ($p = .08$).

Several measures were dropped from the posttest battery at the end of Year 1 because there was no variance in pretest scores. These included the HOME and the Assessment of Fathering Behaviors. Further, a new measure was substituted in Year 2, one selected to measure changes in parent roles which we hypothesized might occur as a result of program involvement. These data will soon be analyzed and we plan to prepare manuscripts reporting our findings for submission in 1985.

Objective 2.0: To coordinate planning and development of the replicable model and its materials with personnel from the State Education Agency, public schools, community service organizations, and professionals from other disciplines.

Local coordination for the demonstration site

Our immediate service mandate under our grant was to recruit participants for each of the three SEFAM components and to deliver regular services. Beginning in Year 1, we established regular correspondence with Seattle-area hospitals, clinics, developmental disability centers, and handicap advocacy groups to inform them of our programs and invite their referrals. After these agencies were notified of our services at the beginning of each year, we continued to keep them informed of SEFAM meetings and special events throughout the year. In this way they could notify their constituencies and clients of particular SEFAM programs of interest.

SEFAM Coordinator Donald Meyer and Co-Facilitator Greg Schell also made regular presentations to community groups to recruit fathers, and to increase the program's visibility. These groups included local develomental disability centers, Kiwanis Clubs, high school groups, parent groups, and local/regional CEC chapters.

One benefit of this coordination with local agencies has been program referrals. Another benefit has been supplementary support for additional program activities. For example, the Seattle-area Eagles has nominated SEFAM for three $1,000 grants for added fathers' and siblings' activities, and two of those grants have already been awarded.

Particularly in our first 2 years, the SEFAM Advisory Council provided direction in tapping local funding sources for supplementary and continued support. Several fathers on the Council were employees of large Seattle corporations with gift funds targeted for local needs. At one father's suggestion we requested funds from the Westin Hotel Corporation, and we were awarded a $600 grant to support the program's increased child care needs.

In 1983 we were urged by one of the SEFAM families to contact their child's grandfather, who is the president of a California private foundation, for support of the local program. This request resulted in a $7,500 gift from the Charter Oaks Foundation which is being used at present to fund the ongoing services for fathers and siblings.

Coordination beyond the local region

The ultimate goal of SEFAM staff has been to disseminate the model to a national audience. It is with this goal in mind that we applied for 1984 Outreach support, and will continue to pursue Outreach funding. In prepartion for SEFAM's Outreach phase, SEFAM staff initiated contacts at several sites of their presentations on the model between 1982-1984. As a result of these contacts, we provided technical assistance to groups of professionals and parents who wished to serve fathers in their community. For example, Don Meyer and Greg Schell presented fathers workshops at the Down Syndrome Congress Meeting in Chicago in 1982. Many of the 85 fathers who attended these workshops expressed interest in starting a fathers program in their community. Don and Greg subsequently visited a group of 9 fathers in the Milwaukee area who had organized a local program, and they provided the fathers with feedback on their efforts. SEFAM staff have also worked with several other groups in Vancouver, B.C., and in Baltimore, Maryland, offering them encouragement and information on how to start a fathers program. In this way we initiated contacts with potential outreach sites and began to develop the skills needed to deliver training and assistance at the conclusion of demonstration support.

Objective 3.0: To design and fieldtest a curriculum using strategies for increasing family members' skills in coping with, interacting with, and educating their child who has special needs, and in fostering a nurturing environment.

One of the major products of this grant is the written guide we have prepared to help others organize programs for fathers in their communities. This guide, A handbook for the Father's Program, has been accepted for production by the University of Washington Press. A draft of the handbook is included in Appendix B. The handbook contains all of the information needed to start a program, recruit participants, plan agendas, guide group discussions, and select guest speakers. It is designed to stand alone or be used in conjunction with training and technical assistance provided by SEFAM staff. The handbook will be reproduced and bound in an easy-to-use loose-leaf format. Readers will have permission to copy pages to share with the participants in their programs. The University of Washington Press has already begun to advertise the handbook, and with access to their marketing department, we anticipate that it will reach a wide audience.

A second product that is a spinoff of this grant is a handbook for siblings of young handicapped children. The Sib Book: Facts and Feelings for

Brothers and Sisters of Handicapped Children will be published in 1985 by the University of Washington Press. It was prepared with the support of a discretionary grant we received from the Department of Health and Human Services as a Project of National Significance in 1982. The idea for the handbook originated in our work with the SEFAM sibling workshops which we initiated at the end of the first year of the project. We identified experiences and concerns young siblings, ages 8-14 seemed to have in common. We wanted to address those concerns for the wider audience of siblings who did not have access to programs like those we initiated for siblings. After reviewing the books on handicaps and handicap experiences that were written for young readers, we found that there were none written for children in the pre-adolescent/early adolescent age range who are beginning to experience their sibling's handicap in new ways. For example, these children have more social interactions that involve their sibling, including peer interactions. They begin to think more about the future, and how their lives will be affected by their sibling's handicap. They begin to have questions and concerns that they find it difficult to share with their parents. With the support we obtained from the DHHS grant, we wrote and fieldtested a book which included our observations and the insights of the SEFAM siblings who attended our workshops. We have had many enthusiastic requests for the book, and we are extremely proud of this contribution to the field.

A final product which is now being completed is a short guide for others who want to offer workshops for siblings. This will be similar in approach to the Father's Program handbook--a how-to guide for professionals in the helping fields who may wish to add siblings to their service matrix. This handbook will be available upon request from the Experimental Education Unit.

Objective 4.0: To develop, fieldtest, and refine materials and products concerning the evolving and final model, including curriculum materials, informational materials, and assessment procedures for measuring behavior change and program impact.

As we describe under Objective 3.0, we have written and are having published handbooks on the two major components of the SEFAM project, the Father's Program and the Sibling Workshops. Both manuscripts have benefited from our work with family members in our programs who provided valuable feedback on the working drafts and final texts. We solicited feedback on these products from a variety of professionals in the greater Seattle area and from across the country, including visiting consultants, special education teachers, parents, physicians, nurses, therapists, and others in the helping professions.

The SEFAM program, by virtue of its innovativeness, has attracted considerable local and national media attention. The Father's Program has been featured on several local television news programs and in an Associated Press article that was carried by newspapers across the country. In fact, one of the families in the Seattle program moved to Seattle from the east coast after they had read about our program in their local paper.

Project staff have prepared a wide variety of written materials on our work in addition to the sibling and father handbooks we have described. We have written four articles that have been published or accepted in peer reviewed professional journals, and 6 book chapters to be published in an edited volume on families of children with handicaps. All of these publications are included in the following list of staff publictions resulting from this project:

Fewell, R.R. (1981). Families of handicapped children (Issue editor). Topics in Early Childhood Special Education, 1(3).

Fewell, R.R. Supports from religious organizations and personal beliefs. In R.R. Fewell and P.F. Vadasy (eds.), Families of handicapped children: Needs and supports across the lifespan. Pro-Ed, Austin, Texas, in press.

Fewell, R.R. A handicapped child in the family. In R.R. Fewell and P.F. Vadasy (eds.), Families of handicapped children: Needs and supports across the lifespan. Pro-Ed, Austin, Texas, in press.

Fewell, R.R., & Vadasy, P.F. (Eds.) Families of handicapped children: Needs and supports across the lifespan. Pro-Ed, Austin, Texas, in press.

Meyer, D.J. Fathers of children with handicaps: Developmental trends in fathers' experiences over the family life cycle. In R.R. Fewell and P.F. Vadasy (Eds.), Families of handicapped children: Needs and supports across the lifespan. Pro-Ed, Austin, Texas. In press.

Meyer, D.J. A sibshop for siblings. Siblings Information Network Newsletter, 1983, 2, (1), Department of Educational Psychology, Box U-64, University of Connecticut, Storrs, CT 06268.

Meyer, D.J., and Vadasy, P.F. 1984. Sibshops at the University of Washington. Siblings Information Network Newsletter, Department of Educational Psychology, Box U-64, University of Connecticut, Storrs, CT 06268. In press.

Meyer, D.J., Vadasy, P.F., Fewell, R.R., & Schell, G. A handbook for the Father's Program: How to organize a program for fathers and their handicapped children. In press.

Meyer, D. J., Vadasy, P. F., & Fewell, R. R. The sib book: A book about facts and feelings for brothers and sisters of children with special needs. In press.

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Vadasy, P.F., Fewell, R.R., Meyer, D.J., & Schell, G. (1984). Siblings of handicapped children: A developmental perspective on family interactions. Family Relations, 33, 155-167.

Vadasy, P.F., Fewell, R.R., Meyer, D.J., Schell, G., & Greenberg, M.T. (1984). Involved parents: Characteristics and resources of fathers and mothers of young handicapped children. Journal of the Division for Early Childhood, 8(1), 13-25.

Vadasy, P.F., Fewell, R.R., Meyer, D.J., & Greenberg, M.T. Supporting fathers of handicapped young children: Preliminary findings of program effects. Submitted for publication.

Vadasy, P.F., Fewell, R.R., & Meyer, D.J. Supporting extended family members' roles: Intergenerational supports provided by grandparents of handicapped children. Submitted for publication.

Copies of many of these publications are attached in Appendix A.

The SEFAM project has also been featured in numerous professional newsletters, newspapers, and in other widely circulated informational publications. For example, the Father's Program was alluded to in a Life magazine editorial on fathers by Loudon Wainwright (See Appendix A). It was featured in the Fatherhood Project's national guide, Fatherhood U.S.A. (Appendix A), and has been visited most recently (December, 1984) by a producer of "60-Minutes," who is interested in spotlighting SEFAM in one of the weekly programs.

*Note: Mrs. Cathleen Moeller is the mother of one of the children in the SEFAM Program. She has been employed as a Parent Coordinator on the SEFAM grant and on the Computer-Assisted Program (CAP) Project at the Experimental Education Unit. In addition to her highly effective interpersonal skills, Mrs. Moeller has written several accounts of her experiences as a parent of a child with Down syndrome.

Our staff take pride and some small degree of credit for the increased awareness of fathers' contributions to the family, particularly the care and development of young children, that we have observed during the course of our grant. The father's role has been the focus of the media in the popular culture, as well as in the professional literature. One result of this increased appreciation of fathers is that programs like SEFAM are recognized as needed and having demonstrable benefits. Unfortunately, at the same time that the need has become apparent to include fathers and other family members in the matrix of agency services, the economy has restricted, and these new programs must compete for reduced resources with older, more established, and often more urgently needed programs. This is the position in which the SEFAM programs have been placed. In our attempts to secure private, long-term funding, we find ourselves competing for a smaller pot of funds that are needed to serve children themselves. In an ironic Catch-22 situation we have become ineligible for support from many sources which fund only new, rather than successful ongoing programs, or which view services to the child through a very narrow perspective, one that is at variance with the ecological perspective we espouse. Certainly this is a transition which must be faced in the life cycle of any program. The SEFAM programs are part of an economic and social milieu, as well as the philosophical movement of helping families to help themselves. The future of our programs will no doubt reflect the confluence of those trends, as much as our own continued efforts to make the programs available to as large a group of families as possible.

Objective 5.0: To disseminate information regarding the evolving and final model to professional, governmental, and general audiences, and to make available materials and products generated by the model program.

As we have described in detail earlier in this report, we are taking to press early in 1985 the two major written products to help others replicate the Father's Program and to address the special needs of siblings. A third major product, a handbook for offering sibling workshops, will be distributed through the Experimental Education Unit.

Throughout the project, staff have made presentations to parent and professional groups to increase awareness of the model. The following is a list of those presentations.

SEFAM Staff Presentations, 1981-1984

SEFAM Staff Member	Group and Year
Rebecca R. Fewell	University of New Mexico Conference, Albuquerque, N. M., 1981
	Office of the Superintendent of Public Instruction, Olympia, WA, 1981
	Region IV Early Childhood Conference, Houston, Texas, 1981

SEFAM Staff Member	Group and Year
Rebecca R. Fewell (Cont'd.)	Early Education Center Outreach Project, Jackson, Mississippi, 1981
	Albuquerque Public Schools, Early Childhood Intervention Program, Albuquerque, New Mexico, 1981
	Developmental Disabilities Conference, Ghost Ranch, N. M., 1981
	Grant Wood Area Education Agency, Cedar Rapids, Iowa, 1981
	AAMD Annual Conference, Vancouver, B.C., Canada, 1981
	North Dakota Council for Exceptional Children, Minot State College, Minot, ND, 1982
	HCEEP of Colorado State University, Ft. Collins, CO, 1982
	CEC 60th Annual Convention, Houston, TX, 1982
	Grant County Developmentally Disabled, Early Childhood Service Organization, Moses Lake, WA, 1982, 83
	AAMD 106th Annual Meeting, Boston, MA, 1982
	6th International Congress of the International Association for the Scientific Study of Mental Deficiency, Toronto, Ontario, Canada, 1982
	University of Missouri HCEEP Demonstration Project, Columbia, MO, 1982
	CEC 61st Annual International Convention, Detroit, MI, 1983
	Region 16 ESD, Amarillo, TX, 1983
	AAMD Annual Meeting, Dallas, TX, 1983
	MacArthur Network Workshop on Affective Development, San Diego, CA, 1983
	State Department of Education, Reno, NV, 1983
	HCEEP/DEC Project Directors and Early Childhood Conference, Washington, D.C., 1983
	Gatlinburg Conference on Research on Mental Retardation, Gatlinburg, TN, 1984

SEFAM Staff Member	Group and Year
Rebecca R. Fewell (Cont'd.)	Educational Service Center, Region 12, Waco, TX, 1984
	AAMD Annual Meeting, Minneapolis, MN, 1984
	A Child Symposium, National Association of Counties, High/Scope Conference, Seattle, WA, 1984
	Educational Service Center, Region 4, Houston, TX, 1984
	Standing Committee on Early Intervention Programs for the Provincial Government, University of Lethbridge, Alberta, Canada, 1984
Donald J. Meyer	The father's role with a Down syndrome child. Plenary session presentation to the Down Syndrome Congress, Portland, Oregon, October 10, 1981.
	Fathers, siblings, grandparents: Forgotten members of a young handicapped child's family? AAMD Region I Conference, Vancouver, British Columbia, November 9 & 10, 1981.
	Programs for fathers and infants. Council for Exceptional Children State Conference, Bellevue, WA, March 19, 1982.
	Serving families of young handicapped children. Council for Exceptional Children National Conference, Houston, Texas, April 13, 1982.
	Fathers and their handicapped children: Research and implications. Summer workshop: early childhood education for the handicapped, University of Washington, Seattle, WA, June 23, 1982.
	The fathers program. Presentations made to parents and staff of Wonderland School, September 29, 1982, Merrywood School, October 13, 1982, and Children's Therapy Center, October 25, 1982.
	A workshop for "fathers only". 10th Annual Down's Syndrome International Congress, Chicago, IL, November 6, 1982. (also at Good Samaritan Hospital, Puyallup, WA, February 15, 1983; Children's Clinic and Preschool, Seattle, WA, February 23, 1983, and Skagit Preschool Association for the Rehabilitation of Children, March 10, 1983).

SEFAM Staff Member	*Group and Year*
Donald J. Meyer (Cont'd.)	Impact of a child's handicap on the family, Seattle Preparatory School Developmental Disability Awareness Day, Seattle, January 27, 1983.
	Concerns of siblings of handicapped children. Washington chapter of the National Society of Adults and Children with Autism, Seattle, WA, March 7, 1983.
	Siblings of handicapped children. North Thurston County School District early intervention program, March 28, 1983.
	Fathers and their handicapped children: Research and implications. Special education graduate class, University of Washington, Seattle, April 26, 1983.
	Programs for siblings at the University of Washington. You are the expert conference, Central Washington University, Ellensburg, April 22, 1983.
	Siblings: Experiences and needs. Children's Clinic and Preschool, Seattle, WA, July 13, 1983.
	Siblings of handicapped children. Washington Advocates for Retarded Citizens, Seattle, WA, July 19, 1983.
	SEFAM's Programs for extended family members. Early Childhood Development Association of Washington (ECDAW), La Conner, WA, July 22, 1983.
	SEFAM: The fathers program University of Washington special workshop in special education: birth to three (EDSPE 496), Seattle, WA, July 29, 1983.
	The fathers program. N.W. Developmental Therapists, Snohomish, WA, September 28, 1983.
	Fathers only workshop. 11th Annual Down Syndrome International Congress, Providence, Rhode Island, October 2, 1983.
	Fathers program. Merrywood School, Bellevue, WA, October 4, 1983.
	Siblings: Unusual problems, unusual opportunities. Fort Lewis parents association, Fort Lewis, WA, November 16, 1983.

SEFAM Staff Member	Group and Year
Donald J. Meyer (Cont'd.)	Siblings: Unusual problems, unusual opportunities, Olympia Public Schools parents program, Olympia, WA, January 28, 1984.
	Siblings: Unusual problems, unusual opportunities, PAVE parent program, Tacoma, WA, February 4, 1984.
	Intervening with fathers as a means of reducing family stress. Research in Action III, Texas Tech University, Lubbock, TX, February 11, 1984.
	Fathers only program. North Shore Infant Development Programme, Vancouver, B.C., January 21, March 31, May 12, 1984.
	Fathers program. Little Red Schoolhouse, Seattle, WA, March 5, 1984.
	Siblings: Unusual problems, unusual opportunities, Parent-to-Parent conference, King County Advocates for Retarded Citizens, March 24, 1984.
	Meeting the underserved needs of fathers of handicapped children. Early Childhood Intervention Conference, Billings, Montana, April 11, 1984.
	Fathers only workshop. Sno-Valley Development Center, Snoqualmie, WA, April 19 & May 24, 1984.
	Support systems in families with handicapped children. Panel member, Council for Exceptional Children National Conference, Washington, D.C., April 25, 1984.
	Programs for fathers, siblings, and grandparents. Guest lecturer in EDSPE 520C University of Washington, May 14, 1984.
	Fathers only workshop. Good Samaritan Hospital, Tacoma, WA, July 25, 1984.
	Supporting Extended Family Members. Guest lecturer, Workshop in Special Education, Birth to Three: Research and Intervention (EDSPE X496TA), University of Washington, July 27, 1984.

Afterword

We would like to express our appreciation to the Department of Education's Handicapped Children's Early Education Program for the support that made it possible for our staff to develop innovative and effective ways of strengthening the handicapped child's family, providing the child with a supportive and nurturing environment. As our earlier progress reports and this Final Report make clear, we have accomplished the objectives we outlined for ourselves and have developed models for serving fathers, siblings, and grandparents that others can use to expand their services to include these family members.

Model development will continue at a less intensive level at the same time that staff increase our efforts to help others in other communities adopt our programs. We continue to offer our local Seattle Father's Program, and we anticipate that it will continue to grow in response to changing family needs and staff refinements. Likewise, we continue to offer the workshops for siblings, and both of these programs are being supported by private funds and gifts. The challenge will be to continue to find support for them now that they are regarded as established ongoing programs. The newest SEFAM program, the Grandparent workshops, is being continued with support from a Parent Training Grant awarded to our local King County ARC, and the SEFAM staff are consulting with that project to provide workshops, prepare manuals for organizing workshops and offering one-to-one grandparent support training, and developing a national newsletter for grandparents. We are pleased to see a program that we piloted under the SEFAM grant expand and take root in a community agency, where its future as an ongoing local service is promising.

Our research will continue at a more intense level under the Field-Initiated Research Studies (FIRS) grant we have received to continue to follow up the SEFAM families for 3 years, and to add a control group to our study. Under this grant we hope to determine whether the positive effects of program participation we observed are maintained, and to expand the focus of our study on a broader range of positive as well as negative family outcomes. These continued research efforts will permit us to contribute to the very young science of evaluating family programs like SEFAM, and to provide data that may be used to influence future policies.

Finally, once we locate the needed support, we will dedicate our energy to the immediate task at hand for a model HCEEP project like SEFAM -- outreach to other communities. We now possess the staff expertise, enthusiasm, and the written materials needed to train others in our model. Further, the interest in the Father's Program is high, and we have requests from over 55 programs to provide their staff with training and technical assistance. We hope that before these circumstances change we will be successful in obtaining funds that will enable our staff to share our skills and experience with others.

The support from HCEEP has benefited SEFAM staff as well as participants. Each of us has had opportunities to pursue our special interests related to early intervention, families, program evaluation, group leadership, research writing and writing for young readers, and adult training. The SEFAM grant has enabled us to use and to develop our talents and interests working for a program in which we shared a strong commitment and enthusiasm. HCEEP support has undoubtedly made each of us more effective professionals, and in this way our grant will continue to have an impact on the field in our future endeavors on behalf of families with handicapped children.

APPENDIX A

Supporting Fathers of Handicapped Young Children:
Preliminary Findings of Program Effects

Patricia F. Vadasy, Rebecca R. Fewell,
Donald J. Meyer, and Mark T. Greenberg
University of Washington

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Abstract

The rationale for and history of an innovative program designed to meet the special needs of fathers of young handicapped children are described. The Supporting Extended Family Members (SEFAM) Father's Program provided fathers with both a regular source of information about their child and access to professional and peer support. The program was evaluated by monitoring changes of both fathers who participated in the program and their wives in the following domains: stress, depression, and support systems. Research measures are described which were designed to assess changes in these targeted domains. Preliminary results indicated that parents who participated in the pilot program reported lower levels of stress and depression and higher levels of satisfaction with social support than parents who were newly enrolled in the program. The findings are discussed in light of possible mediating factors for the observed results. Recommendations are made for improving the quality of data on the effects of early interventions on family members.

Responding to Needs of Fathers of Handicapped Young Children: Preliminary Findings of Program Effects

Families are unique groups of individuals, each with distinct traits, who function in diverse and changing environments. Dynamic units in themselves, families respond both to events that are naturally occurring and experienced by most families, and to crises which place individual families at risk for unusual stress. One of these crises is the birth and rearing of a handicapped child.

Each family is characterized by its own cycle of formation, growth, development, maturity, and dissolution. This cycle is often altered by the birth of a handicapped child. Parental expectations for the child's future must be revised. Family reponsibilities for the care of the child most often increase, sometimes dramatically, and often last for a longer period of time than for a nonhandicapped child. In most families, the mother experiences the greatest effects of these increased and prolonged child care responsibilities. For this reason, most programs and services for handicapped young children have focused on the needs of the child and of the mother as the primary caregiver. And, because much of the research on this population has been conducted to evaluate existing interventions, most of the data on the impact of the handicapped child concern the mothers' experiences.

Several factors, however, have contributed to a growing appreciation of the father's experience of his child's handicap, and the father's changing role in his young child's life. The growing number of working mothers and the relaxation of traditional parent/sex roles have contributed to the need and desire of fathers to assume increased responsibility for their child's care and development. At the same time, a growing body of literature on father-child interactions demonstrates that fathers have a unique and significant effect on their children (Clarke-Stewart, 1978; Lamb, 1977). The father-child relationship is jeopardized when the child is handicapped. Fathers of handicapped children may experience a loss of self-esteem (Cummings, 1976; Ryckman & Henderson, 1965), increased depression (Love, 1973), and marital distress (Farber & Jenne, 1963; Holt, 1958; Lonsdale, 1978; Reed & Reed, 1965).

In 1980, we undertook to develop a model program that would address the special needs of fathers with young handicapped children. The program was designed to be "proactive" in the sense that it would support fathers and strengthen their ability to cope with the ongoing stresses resulting from their child's handicap. We recognized that each family would have personal coping strategies to share with other families in the program. One of our goals was to facilitate that sharing. In addition, we planned to provide fathers with information and a social support system that would increase their ability to handle the stresses involved in raising a handicapped child. At the same time that we designed our program model, we planned a longitudinal evaluation of program effects. Our long-term goal for this evaluation was to describe the interaction of individual characteristics and situation variables that might affect program impact. It was expected that this information would enable us and others who might use the program to understand how it enables certain families to cope more effectively than others with similar stresses. This article describes that model for serving fathers of handicapped young children and the research we have conducted to date to evaluate the effects of the program.

Program History

The Father's Program originated in 1978 as a pilot program that was offered twice a month for fathers and their handicapped babies. The program was held at the Experimental Education Unit of the Child Development and Mental Retardation Center at the University of Washington for 9 to 10 months each year. Each class was 2 hours long and was held on Saturday mornings. The program was originally staffed by two volunteer male graduate students in early childhood special education (one the father of a child with Down syndrome). In 1980, the Father's Program became one component of the Supporting Extended Family Members (SEFAM) Program, a federally funded Handicapped Children's Early

Education Program (HCEEP) project. Two other SEFAM components served siblings and grandparents. The original two volunteers continued to cofacilitate the SEFAM fathers component.

The Program Model and Rationale

Each Father's Program session offered the fathers an opportunity to acquire and refine their skills in interacting with their children; to obtain information about child development and the nature of their child's handicap; to share their worries and concerns with the group leaders and with other fathers; and to meet with guest speakers who were invited to discuss selected topics of special interest to the fathers.

Others have found that social support such as that provided to fathers in the program: (a) serves as a buffer in times of stress (Antonovsky, 1979; Caplan, 1974; Cassel, 1976; Cobb, 1976; Henderson, Byrne, Duncan-Jones, Adcock, Scott, & Steel, 1978; Pearlin, Lieberman, Menaghan, & Mullan, 1981); (b) may mediate parent stress and prevent negative parent-child relations (Powell, 1979; Unger & Powell, 1980); and (c) may have both direct and indirect effects upon the child (Cochran & Brassard, 1979). For example, Crnic, Greenberg, Ragozin, Robinson, and Basham (1983) reported the positive effects of social support on mothers' attitudes and behaviors, life satisfaction, and their infants' responsiveness to the mother in observed interactions.

Each Father's Program meeting followed a similar format. After the fathers and their children arrived and had time to socialize briefly, graduate students provided child care while the fathers participated in what we called the Father's Forum. This 40-minute-long group session gave fathers a chance to discuss issues or problems that were of concern to them. The two program leaders served as facilitators for these discussions, keeping the discussion on topic, and ensuring that all fathers had an opportunity to contribute. After the Father's Forum, the children rejoined their fathers, and the program leaders introduced activities the fathers could practice with their children. About mid-morning, the group would break for a short snack time which provided a second opportunity to socialize. After the break, the children again were cared for by graduate students while the fathers met with a guest speaker who had been invited to address a particular topic of group interest (e.g., a dentist who explained how to find dental care for a handicapped child; a lawyer who described how to set up wills and trusts; and a pediatrician who discussed the efficacy of a controversial vitamin therapy program). Families were notified in advance regarding the name of the guest speaker and the topic to be discussed. Mothers were invited to attend this portion of the program, and those who were interested often joined their husbands at the snack break.

Several times each year, "fathers only" meetings were held when the fathers met without their children and the men spent the entire morning in extended discussion, or meeting with a panel of guest speakers. Several annual family meetings were also held when mothers, siblings, grandparents, and other family members were all invited to take part in social activities.

Research Questions

Like most intervention programs, the Father's Program was based upon certain assumptions about the benefits to fathers of regular peer contact, access to accurate information, and opportunities for successful interactions with their children. We assumed that program participation would reduce the depression that fathers of handicapped children have been reported to experience; that it would strengthen fathers' self-esteem by helping them become more competent, informed parents; and that it would offer fathers the social support that has been associated with successful coping during periods of stress and crisis. Further, we hypothesized that fathers' participation in the program might even have second-order effects upon their wives, who would experience increased support in their roles. Therefore, the wives of the men in the program were also asked to participate in the evaluation.

The SEFAM research design focussed on monitoring changes in the following domains:

Father's and mother's stress level. The information and support the program provides fathers was hypothesized to reduce their stress, and further, to reduce the stress experienced by wives who, in turn, receive increased support from involved husbands.

Father's and mother's depression level. The feelings of isolation and of being overwhelmed by a young child's handicap often result in depression. A major goal of the program was to address those problems by providing fathers with practical information to manage daily concerns, and with a base of social support which fathers could access when needed. Wives of fathers who had these resources would be expected to benefit from them and to experience less depression than wives of men without such resources.

Father's and mother's support systems. Fathers in the program gain access to both professional and peer supports. Program staff and guest speakers offer the fathers their support through sharing information and acknowledging the fathers' concerns. The program is organized to encourage fathers to develop informal peer supports. Further, the activities planned for all family members offer mothers opportunities to meet and form friendships with other families who have similar concerns.

Method

Subjects

This report is based on the preliminary analysis of data collected during the first year of the project. The families who participated in the program were predominantly white, middle class, and well educated. The mean age of their children was 26 months. Thirty percent of the parents had a bachelor's degree; 35% of the fathers and 17% of the mothers completed some graduate work; 40% (adjusted) of the families had combined gross incomes of $30,000 and above. The independent variable was program participation, and subjects were divided into two groups, those who had been enrolled in the pilot program for periods of 1-3 years (n = 7), and those who were newly enrolled in the demonstration program (n = 16).

Dependent Measures

We examined changes in the domains described above by administering the first four instruments described below to both participating fathers and their wives. The last measure was administered to fathers only:

1) Beck Depression Inventory (Beck, Ward, Mendelson, Mock, & Erbaugh, 1961). A 13-item version of the original self-administered questionnaire presents groups of statements concerning the respondent's current sadness,

pessimism, failure, guilt, fatigue, self-esteem, dissatisfaction, disappointment, self-destructiveness, self-motivation, interest in others, decisiveness, and appetite. Beck et al. (1961) reported reliability correlations between Beck scores and clinicians' ratings of 0.65 and 0.67 ($p < .01$).

2) Family Environment Scale (FES) (Moos, 1974). The FES consists of 90 true/false items grouped into 10 subscales which discriminate the social climates of different family types. The subscales measure three dimensions of family environment. The first group assesses family relationships. The second subscale group assesses personal growth and development. A third group of subscales measures system maintenance. Moos reported an internal consistency for the 10 subscales ranging from 0.64 to 0.79; average subscale intercorrelations of 0.20; and 8-week test-retest reliability of 0.68 to 0.86.

3) Inventory of Parents' Experiences (IPE) (Crnic, Ragozin, Greenberg, & Robinson, 1981). This is a 45-item questionnaire on which the parent indicates the number of professional, neighborhood/community, casual friends, and personal/marital types of contacts, and the parent's satisfaction with each type of support.

4) A short form of the Questionnaire on Resources and Stress (QRS-F) (Friedrich, Greenberg, & Crnic, 1983). The original QRS (Holroyd, 1973) is a 285-item self-administered true-false questionnaire with 15 scales describing the effects of the handicapped child on family members (e.g., poor health, time demands, pessimism, financial problems). Friedrich et al. (1983) developed a short 52-item version which includes four factors: parent/family problems, pessimism, child characteristics, and physical incapacitation. The authors reported a correlation between the short form and the QRS total score of 0.997 ($p < .001$). A validation study by these authors showed a significant correlation between four QRS-F factors and three independent measures of depression, socially desirable responses, and child behavioral problems.

5) Parent Needs Inventory (PNI) (Robinson & De Rosa, 1980). Originally developed as a Q-Sort, the PNI was adapted by SEFAM staff as a self-rating scale. It is designed on the assumption that every person has both an 'ideal' and a 'real' self. The PNI measures self concept by describing the relationship between parents' ratings of their real and ideal selves. The closer to 1.00 a parent's score is, the closer the match between the 'real' and the 'ideal.' Statements describe

parents' real and ideal assessments of the grief process, knowledge of child development, and knowledge of local resources. Reliability scores for items in each section in relation to the entire inventory were: grief 0.64, child development 0.83, and local resources 0.87. Four-week test-retest reliability correlations were 0.64, 0.33, and 0.47 in the three respective areas.

Our rationale for administering a comprehensive assessment was to identify potentially useful measures for monitoring program impact. Somewhat like Tolstoy (1876), we hypothesized that all stressed families are stressed in their own fashion. In some families, factors like the parent's social support or father's depression might be affected by program participation, whereas in other families, parents' roles and responsibilities or family organization might change over the course of a father's involvement. Our intention was to gather longitudinal data on a wide variety of potential factors that might be correlated with program effects, with a view to constructing and recommending an evaluation package that can be employed by others.

Method of Analysis

To examine the effect of program participation of fathers, a series of one-way ANCOVAs (analysis of covariance) were utilized with child's age, father's occupation, and father's education serving as covariates. The effects on mothers also utilized a series of one-way ANCOVA s with child's age and mother's education as covariates.

Results

Tables 1 and 2 summarize the results of significant findings on the selected measures for fathers and their wives.

Beck Depression Inventory. Fathers who had participated in the pilot program had total Beck scores that were lower than total scores for newly enrolled fathers ($\underline{p}<.01$). Program fathers also differed from newly enrolled fathers on several individual Beck items: they reported less sadness ($\underline{p}<.001$), less fatigue ($\underline{p}<.05$), more satisfaction ($\underline{p}<.05$), less pessimism about future concerns ($\underline{p}<.05$), greater success vs. failure as a person ($\underline{p}<.05$), less guilt ($\underline{p}=.01$), and better decision-making ability ($\underline{p}<.05$). Wives of men who had been enrolled in the pilot program reported lower feelings of failure ($\underline{p}=.05$) and more positive feelings of attractiveness ($\underline{p}<.10$) than wives of newly enrolled men. However, there were no differences between groups on the total Beck score for the wives.

Family Environment Scale. When child's age was covaried, fathers who had been in the pilot program reported higher levels of expressiveness $F = 2.9$, $\underline{p}<.01$ than new enrollees, as did the wives of program fathers $F(1,19) = 3.2$, $\underline{p}<.10$ when mothers' education level was entered as a covariate. Wives of program fathers tended to also report higher levels of family independence (p<.10). There were no other differences between groups on the FES.

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Inventory of Parents' Experiences. Program fathers reported more satisfaction with people to share good/happy times with (p<.05), as did their wives (p<.05), compared to parents who had just entered the program. Program fathers also reported more satisfaction with people with whom they could share their most private feelings (p<.05), greater satisfaction with their level of religious involvement (p<.05), and greater satisfaction with their neighborhood involvement (p=.06). Finally, wives of the program fathers reported more satisfaction with the time they had to themselves than wives of the newly enrolled fathers (p<.08).

Questionnaire on Resources and Stress. Program fathers reported less stress due to the child's incapacitation (p=.05), and fewer total problems (p=.01) than newly enrolled fathers. Wives of the fathers who had been in the pilot program reported less stress due to the child's characteristics (p=.08), than wives of men who had just entered the program.

Parent Needs Inventory. For this measure the fathers' mean scores were calculated for the differences between "real" and "ideal" responses on the three PNI sections: the grief process, knowledge of local resources, and knowledge of child development. There was a significant difference ($p < .05$), between the means of program fathers and newly enrolled fathers on the grief index when means were adjusted for child's age, father's education, and father's occupation. Program fathers' mean score on the grief index (0.86) was significantly closer to 1.0 (a score reflecting a perfect match between "real" and "ideal" selves) than means for newly enrolled fathers. When mean scores on the knowledge of local resources index were compared, program fathers' adjusted mean (1.0) differed significantly ($p < .05$), from the means for newly enrolled fathers, which reflected greater differences between their ratings of their real and ideal selves. Finally, when mean scores on knowledge of child development were compared, the program fathers' adjusted mean (1.04) differed significantly ($p < .01$), from the mean for newly enrolled fathers, reflecting a closer match between the real and ideal for the fathers in the program.

Discussion

These preliminary findings indicate that fathers who participated in the SEFAM pilot program differed in several areas from fathers who had not yet been involved in the program. In addition, the findings indicate that the wives of the program fathers may also have benefited from their husbands' participation. Fathers who participated in the program reported less stress and depression, and greater satisfaction with social supports than newly enrolled fathers. The wives of the program fathers also reported second-order effects in these areas. These findings must be tempered, however, in light of the small size of our sample (n = 23), as well as the nonrandom assignment of subjects into the two groups. All subjects were self selected, and further, the new fathers differed from the fathers who were in the pilot program by virtue of having younger children.

Although these data permit us to compare these two groups of fathers of handicapped children along the dimensions we noted above, our lack of a control group prevents us from knowing how the fathers in the study differ in these areas from fathers of nonhandicapped children matched for specific characteristics such as age, race, education, and income.

To this point we have focussed on the differences between the two parent groups. However, we also found many similarities between the groups. First, both sets of parents had relatively low levels of stress and high life satisfaction. There are many possible explanations for these similarities. Other researchers (Farber, 1960; Grossman, 1972; Moore, Hamerlynck, Barsh, Spieker, & Jones, 1982; Rosenberg, 1977) have found that class, education, and income are inversely related to stress, and as we noted, the education and income levels of the parents in this study were higher than average. Stress in parents of handicapped children has also been related to the age of the child, with stress increasing as the child grows older, becomes more difficult to care for, and falls farther behind peers (Birenbaum, 1971; Bristol, 1979; Farber, 1959; Farber & Rykman, 1965). The parents of the young children in the SEFAM program may actually be experiencing less stress in their lives at the time they are assessed than they will experience later in their child's life. This would have implications for determining when external supports like this intervention program are most needed by parents with handicapped children.

Another child characteristic in addition to age may contribute to the positive self reports of the parents in this study. Parental stress appears to be higher in parents of severely handicapped children than in parents of mildly or moderately handicapped children (Breslau, Staruch, & Mortimer, 1982; Korn, Chess, & Fernandez, 1978; Moore, et al., 1982; Nevin & McCubbin, 1979). Most of the children in the SEFAM program were not physically handicapped, and the most common handicap was Down syndrome (n = 20). Although a few children in the program had severe physical and mental delays and medical complications, most of the children were moderately delayed. The physical demands they posed for their parents, in most cases, were not significantly greater than those experienced by parents of nonhandicapped children of the same age.

Finally, the parents in this study had access to support systems that may have ameliorated the stress of caring for their handicapped child. All of the parents came from two-parent families and had available the physical and emotional support of a spouse. Stress has been found to be higher in single-parent families with a handicapped child than in two-parent families (Beckman-Bell, 1980; Holroyd, 1974). In addition, the wives of the program fathers had the special advantage of their husbands' involvement in the program. Not only are the fathers in this study likely to be more informed about and competent in caring for their children than most fathers of handicapped children, the SEFAM fathers are possibly self selected, being more motivated and interested in their children by the very nature of their participation in such a program. This interest and competence in caring for their children would serve as a regular support to their wives, but would make these fathers potentially unrepresentative of the "normative" father of a handicapped child.

Both parents indicated satisfaction with the support networks available to them, including medical professionals. Many families in the SEFAM program were involved in church activities. This involvement may reflect a strong value system which would help a family come to terms with the birth of a handicapped child. Religious involvement may also offer many of these families access to material support and assistance from other church members and from services sponsored by their church.

These findings, which we regard as preliminary, do not yet permit us to say whether we are serving a special group of parents who have come to the program equipped with their own support systems, and who are preselected for characteristics that are associated with good family outcomes. The positive nature of these preliminary findings, however, supports the need for continued follow-up of these families to determine if program effects are maintained over time, and future follow-up assessments of all SEFAM families are planned at yearly intervals. It is hoped that these longitudinal data will shed light on families' developmental experiences as the child matures. Comparative data are also needed on families with nonhandicapped children to better understand variables other than the child's handicap that influence the parents' stress and their social support networks.

Finally, we would call our readers' attention to outcomes of importance which we do not report, but which would further enhance the ecological validity of evaluations of early interventions. It is not only proper that such evaluations include all significant family members in their samples, but also that they avoid a negative bias and examine both ends of the coping continuum, taking note of positive as well as negative outcomes. The negative biases of professionals to expect family pathology, as well as the choice of available measures have influenced the choice of outcomes in many studies. Yet more recent attention is being given to families' potential to make positive adaptations under adverse circumstances, and in some cases, for family members to benefit from their stressful experiences with clearly defined values, new information and skills, and stronger problem-solving abilities. Efforts to refine methods of describing these positive outcomes will help us to understand the full spectrum of family outcomes and document support for future family policies.

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Table 1

Means*, Standard Deviations, and Significance of Paternal Dependent Variables by Father Participation (Analyses of Covariance)

	Program Fathers		New Fathers		F ratio
Dependent Measure	Mean	S.D.	Mean	S.D.	(1,14)
Beck Depression Inventory					
Total Score	2.20	2.8	7.19	5.2	9.4, $p < .01$
Sadness	0.00	0.0	0.52	0.6	15.5, $p < .001$
Fatigue	0.20	0.5	0.83	0.6	6.9, $p < .05$
Satisfaction	0.02	0.4	0.80	0.6	7.0, $p < .05$
Future Concerns	0.05	0.5	0.68	0.6	4.9, $p < .05$
Success/Failure	0.00	0.0	0.35	0.5	6.5, $p < .05$
Guilt	0.04	0.1	0.55	0.8	7.7, $p = .01$
Decision-Making	0.17	0.4	0.58	0.6	5.3, $p < .05$
Inventory of Parent Experiences					
Sharing Happy Events	4.01	0.5	2.79	0.8	5.0, $p < .05$
Sharing Private Feelings	4.17	0.8	2.65	1.0	5.6, $p < .05$
Religious Satisfaction	4.33	0.5	3.03	0.8	4.5, $p < .05$
Neighborhood Satisfaction	4.02	0.8	2.70	0.9	4.1, $p = .06$
QRS-F					
Child's Incapacitation[a]	4.16	0.9	5.71	1.0	4.5, $p = .05$
Total Problems[b]	0.86	3.9	6.51	3.4	7.9, $p = .01$

* All means are adjusted for the covariates of child's age, father's education, and father's occupational status

[a] Child's chronological age was significant covariate ($p < .05$)

[b] Father's education ($p < .05$) and occupation ($p < .05$) were significant covariates

Table 2

Means*, Standard Deviations, and Significance of Maternal Dependent Variables by Father Participation (Analyses of Covariance)

	Wives of Program Fathers		Wives of New Fathers		
Dependent Measure	Mean	S.D.	Mean	S.D.	F ratio (1,19)
Beck Depression Inventory					
Success/Failure	0.00	0.0	0.30	0.6	4.3, $p = .05$
Appearance/ Attractiveness	0.04	0.4	0.74	0.8	3.5[b], $p < .10$
Inventory of Parent Experiences					
Sharing Happy Events	4.01	0.5	2.79	0.8	5.0, $p < .05$
Satisfaction Time to Self	3.74	1.0	2.45	0.9	3.4[c], $p < .08$
Family Environment Scale					
Family Expressiveness	3.30	1.3	2.42	0.8	3.2, $p < .10$
Family Independence	3.31	0.8	2.48	0.9	3.2, $p < .10$
QRS-F					
Child's Characteristics	5.67	2.0	7.83	2.1	3.7[a], $p = .08$

* All means are adjusted for the covariates of maternal education and child's age. No significant effects were found for the covariates.

[a] df (1,15)

[b] df (1,18)

[c] df (1,19)

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The View from Here
by Loudon Wainwright

Life with—and without—Father

If I remain still, if I am alone and silent long enough to hear the sound of my own blood or breathing or digestion above the rustling of leaves or the whir of the refrigerator, my father is likely to turn up. He just arrives unbidden in the long-running film of my thoughts, like Hitchcock in his pictures, and he looks for all these 40-plus years of disembodiment much like himself, big and sandy-haired with freckles on the backs of his hands, perhaps a bit more diffident in the way he holds himself than I remember. He doesn't stay long, and as far as I can tell his visits have no message. Yet—even though years of therapy have led me to make the dark-whistling claim that he's finally dead and gone—my father, who died when I was 17, continues to be my principal ghost, a lifelong éminence grise, and only my own end will finish it.

Now and then he makes other appearances. Just the other day an old friend, going through scrapbooks that had been in his mother's house when she died, found pictures of our two families together at a beach picnic at least 50 years ago. The friend kindly gave me some of the snapshots, and there in several of them was my father in a two-piece bathing suit. My mother, 80 this year, was there, too, her beauty and huge eyes shocking across half a century, and so was I, a shy eight-year-old hiding behind a soggy sandwich. I kept looking back to my father. He was about 35 at the time, his body getting a little thick, his hair thinning at the top of his high forehead. But as he somehow always does, he seemed older, more substantial on that beach than I am now, and I studied those yellowing prints as if they might hold great discoveries, my own scrolls from the Dead Sea caves, about the truth of the connection between him and me.

Personal considerations aside, it seems to me that fatherhood as a subject for analysis and study is undergoing a renaissance these days. The topic has always fascinated people deeply, but there are new dimensions to its exploration. Many are taking sudden and lively notice of this often "forgotten" parent and his untapped potential for increased usefulness, stability and growth within the family and, indeed, the civilization.

Quite possibly set off by the rise of the women's movement and the resultant increase in the amount of time that men now actually spend with their children and devote to their care, this new interest in fatherhood is taking many forms. Social service organizations have set up long-term studies of fathering behavior. Colleges and community centers in hundreds of locations around the country have designed courses for the education of men coping with the daily business of taking care of kids. * A group of 20 fathers in Seattle meets every other week for a full school year to study and compare notes on the particular problems of dealing with their handicapped children. There is widespread demand for child-rearing courses for single or divorced fathers, and the Ford Foundation is setting up a program for the guidance of teenage fathers around the U.S. In one Massachusetts experiment prisoners are counseled on such special dilemmas as how to tell their children about their crimes and how to help them not follow in their footsteps.

Considering the longevity of the breed, there's something a little odd—after all these aeons—about the discovery of fathers and fatherhood. Still, there's something enormously healthy about it, especially in view of the fact that much of the current demand is stimulated by the men themselves. It's as if they (we) suddenly woke up and discovered how huge a slice of life they (we) had been missing and insisted on a greater participation in the nurturing process. A lot of male aloofness over centuries has clearly been a matter of choice (It's woman's work—I have grander things to do). But the pressures of the culture have been very strong, as well, and powerful women were certainly among those who perpetuated the notion that men should stay in their place. That place has most often been somewhere far, far out of the daily line of fire; my father knew how to find refuge there, and so, in my own fathering days, have I.

It has always been easier for me, however painful, to think about my father's problems with the job than about my own. For some reason, his failures are more forgivable than mine. And there have been a couple of books published recently whose examinations of the whole matter put the books high on my discomfort index. One, *Father, the Figure and the Force* by Christopher P. Andersen, cruises across the subject with examples drawn from the author's own experiences and those of many others, whose casually dropped big names—Sophia Loren, Henry Fonda, Laurence Olivier, Dan Rather—somehow make the cases a little less telling for me. The other book, by Suzanne Fields and titled *Like Father, Like Daughter* (not to be confused with Dr. William Appleton's more psychiatrically oriented *Fathers and Daughters* of two years back), is fleshed out with examples from more common stock, anonymous interviewees whom Fields persuaded to answer a lot of rough questions about themselves and Daddy, as he is often called in her book.

This is a volume I was quite prepared, even eager, to dislike, since I knew in advance that reading it would make me feel that I have made—or fantasized making—just about every mistake that a father can make with his daughter. And I do have a few minor caveats about it. The book is repetitive, not very well organized, and here and there it gushes, especially about the author's father, who always seems to be opening a bottle of champagne. Once in a while, Fields engages in a strange overkill in citing her authorities, i.e., "According to Carl Jung, the Swiss psychoanalyst. . . ."

Still, with the sometimes horrifying details of its case histories, the book packs a big punch. The pages teem with fathers who are distant, overprotective, manipulative, seductive, cruel (often because they can't deal with their own strong sexual feelings about their daughters) and ferociously jealous. A lot of the men described here are incredibly callous, including one father who just brushes off his daughter's frantic protests and shows—for a house full of virtual strangers—an old home movie that consists of her clumsy and adolescent attempts to dance.

But—surely in part because of the author's good feelings about her own father—the book has a sense of balance that makes up for some of the scarier stuff. There are caring fathers here, and there are fathers who make loving, wise and even selfless decisions that help their daughters along the way to growth and greater self-esteem. Reading about them, I can even acknowledge that my own efforts haven't been all bad. For some of the fathers in Fields's book, a solid understanding with their children was not achieved until near the ends of their lives. My father went too soon for much of that. I didn't have a clue how angry at him I'd been—and how much he'd mattered to me—until years later. As for me and my own children, I'd prefer straightening some of it out sooner. Considerably sooner. ◆

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FATHERHOOD U.S.A.

"That's fathering."

The First National Guide to Programs, Services, and Resources for and about Fathers

Debra G. Klinman, Ph.D. • Rhiana Kohl
The Fatherhood Project at Bank Street College of Education

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participated—and from their wives—is positive. They report an increase in father-child interaction and in the emotional support and discussion between spouses in relation to their "special" child.

WASHINGTON

UNIVERSITY OF WASHINGTON
CHILD DEVELOPMENT & MENTAL RETARDATION UNIT
Address: Experimental Education Unit WJ-10, Seattle, WA 98195
Contact: Dr. Rebecca Fewell, Project Director,
Donald Meyer, Project Coordinator
Phone: (206) 543-4011
Program: "Supporting Extended Family Members (SEFAM)"
When: Weekends
Format: Bi-monthly 2-hour sessions throughout the school year
Fee: None

SEFAM was funded by the U.S. Department of Education in 1981 as a three-year demonstration program serving the fathers of handicapped infants and toddlers (birth through 3 years). Since the responsibility of caring for a child with special needs is sometimes overwhelming, the involvement of the child's father can be especially important--but fathers have traditionally been left out of early intervention programs. SEFAM's goal is to help fathers understand and enjoy their handicapped child, so that they can play an active and informed role in every stage of child development. The program also works with other underserved members of the handicapped child's family, notably ~~mothers~~, siblings, and grandparents.

A group of about 30 fathers bring their handicapped youngsters with them for Saturday morning play and discussion sessions. Many of the children are mentally retarded; others have physical handicaps or a combination of difficulties. All sessions are led by two male staff members; both are trained in special education, and one is the father of a young handicapped daughter.

Participants begin their morning with a cup of coffee, casual discussion, and free play with their children in a gym equipped with padded floor mats and toddler toys. Then, the dads meet alone for a "share time" when they can discuss common concerns and issues. The men provide each other with a great deal of

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support and understanding. United again in the playroom, dads and toddlers join in songs, dances, exercises, and a group snack. Finally, an informative session is presented by a guest speaker, who addresses some topic of particular interest—such as setting up trusts and wills for the handicapped child, or selecting developmentally appropriate toys.

While working directly with fathers and handicapped youngsters, the SEFAM staff conducts research about family stress and develops a model parent-child curriculum which will enable others to replicate their work.

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Siblings of Handicapped Children: A Developmental Perspective on Family Interactions*

PATRICIA F. VADASY, REBECCA R. FEWELL, DONALD J. MEYER, AND GREG SCHELL**

Research on the impact of the handicapped child on siblings has indicated several sibling characteristics that are associated with increased sibling vulnerability to stress and other problems. The identification of sibling risk factors, in and of itself, however, does not help us understand differences in sibling outcomes. A transactional framework describing family interactions and their effects on the family's development is presented in order to examine ecological variables influencing family adaptation.

Research on families of handicapped children is clarifying the reciprocal nature of the relationship between parents and the handicapped child. The impact of the child upon the mother has been well documented (Gallagher, Cross, & Scharfman, 1981; Gath, 1978; McMichael, 1971; Seidel, Chadwick, & Rutter, 1975; Tew & Laurence, 1975). However, the father as well as the mother, and the intricate web of relationships that exists among family members—the parents' marriage, their relationships with the handicapped child's siblings—are affected by the handicapped child's characteristics and special needs. A slowly growing body of literature describes the impact of the child's handicap upon the father (Cummings, 1976; Farber, Jenne, & Toigo, 1960; Gallagher et al., 1981; Gath, 1978; Tallman, 1965). Fathers share some of their wives' concerns, yet experience emotions and worries that are quite different (Gumz & Gubrium, 1972; Hersch, 1970; Love, 1973). This information on paternal experiences and needs enables professionals to plan services and programs that respond to both parents' needs, and to foster parents' attachment to and understanding of the handicapped child.

The handicapped child's impact upon siblings has been less well recognized and understood by professionals who serve these families. Quite often the needs of the handicapped child's siblings are overlooked by

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Key Concepts: families of handicapped children, family crises, family ecology, family-child effects, parent-child relationship, role behaviors, sibling relationships.

(Family Relations, 1984, 33, 155-167.)

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parents and professionals. Young, nonhandicapped siblings are often reluctant to approach adults and discuss their feelings or problems that embarrass them. Their problems are often overshadowed by those of their handicapped brother or sister and may not come to a parent's attention. A closer examination of the small body of research to date on siblings, however, suggests that these children may be at risk for emotional problems and increased demands as a result of their brother or sister's handicap. Sisters of a handicapped child appear to be most vulnerable. Parents are often unprepared or unable to help their nonhandicapped children adjust to their sibling's handicap and prepare for the future. In most families, the handicapped child's needs take precedence over other family members' needs. The needs of siblings are also easily overlooked by professionals who remain focused upon the mother-father-handicapped child triad's more familiar, and often more immediate needs. Several reports suggest, however, that when siblings of handicapped children are involved in training and therapeutic programs, the entire family may benefit (Collins, 1981a, 1981b; Miller & Cantwell, 1976; Murphy, Pueschel, Duffy, & Brady, 1976; Weinrott, 1974).

This article reviews the literature on siblings of handicapped children, and highlights variables identified with increased sibling vulnerability to stress and emotional problems. Methodological weaknesses of sibling research to date are discussed, particularly the need to examine dynamic as well as static factors that influence family adaptation. For example, many of the studies that follow have isolated parent and child characteristics associated with increased stress. Few studies have considered the setting in which families interact over their life cycle; yet the context of family behaviors must be examined to understand how family members respond to changing demands in different settings over the family's life span. Siblings, as well as fathers, have needs that have been often overlooked by policies that focus solely on the handicapped child or the child's mother. Yet if it is desirable to enable the child's family to maintain and care for the handicapped child in the home, strategies must be identified to help all family members meet the ongoing stresses they will experience over the family's life span.

Static Variables

The Effects of Age, Birth Order, and Sex

Grossman (1972) conducted one of the most well-known studies of a group of 83 nonhandicapped college age siblings of retarded children. The sample included 34 lower and lower-middle-class students from a community university, and 49 middle to upper-middle-class students from a private university. About 17% of the handicapped siblings were severely/profoundly retarded, 35% moderately retarded, and 48% mildly retarded. Approximately 45% of the students surveyed reported that they had benefited from having a retarded sibling. The benefits they cited included: increased understanding of other people; more tolerance and compassion; and, greater appreciation of their own good health and intelligence. Forty-five percent reported negative experiences including guilt, shame, a sense of being neglected and defective, and negative feelings toward their retarded sibling. Community university women with more severely retarded siblings functioned better than those with mildly retarded siblings, while the severity of retardation was not related to adaptation for the private university students. These findings emphasized each family's unique response to a handicap, influenced by family social class, family size, and age and sex of siblings. For example, community university women from large families had better coping and psychological health than women from small families, although it should be noted that siblings from small families were underrepresented in Grossman's study.

Grossman also found that the normal child in a two child family experienced more pressure to make up for the retarded child, especially when the retarded child was a son. All students were more embarrassed by a handicapped sibling of the same sex. Older siblings of both sexes received higher coping scores than siblings who were younger than the retarded child. Grossman described coping as the sibling's overall social adaptation, relationship with the retarded child, and the effect of the retarded child upon the sibling's self-esteem. Younger brothers of mentally retarded males appeared to be at greatest risk; this finding prevailed across social classes. Private university students with accepting parents and family demonstrated better adaptation than those with less accepting parents. Parent reactions had little influence on community university students, perhaps because this latter group experienced more hardships as a result of their sibling's handicap than the private university students. Grossman's findings are subject to the limitations of recall bias on the part of the respondents, and self-selection of less affected siblings.

Grossman's findings on the effects of birth order and sex of affected siblings were similar to those reported by Breslau, Weitzman, and Messenger (1981), who studied 239 families of disabled patients 3-18 years old. Handicaps of the disabled included cystic fibrosis, cerebral palsy, myelodysplasia, and multiple handicaps. The nonhandicapped siblings were 6-18 years old. Mothers were asked to rate how the handicapped child affected nonhandicapped siblings. The handicapped child's diagnosis or disability level had no significant effect upon the siblings' mean scores on Langner's Psychiatric Screening Inventory. The siblings' sex and age also had no main effects upon their behaviors. Relationships were found between the siblings' birth order and sex: younger male siblings had greater psychologic impairment, as measured on Langner's Inventory, than female siblings who were younger than the disabled child; older sisters had more impairment than the older brothers of the disabled children. The findings were replicated when the authors controlled for age. The data reported by Breslau et al., however, were second hand in origin, and no direct assessments of the siblings were made.

Gath (1972, 1974) included siblings in several studies of families with handicapped children. A 1972 study of 36 school age siblings of 22 children with Down's syndrome, 35 school age siblings of 21 children with cleft lip/palate, and 71 matched controls did not reveal any differences in the degree of behavioral disturbance experienced by the groups. The later study of 104 families with a child with Down's syndrome living in the home and a group of matched controls reported increased disturbances in the older sisters of the retarded children, especially first born sisters who were more than 3 years older than the child with Down's syndrome. Gath's data were derived from behavioral scales completed by the siblings' parents and teachers and did not include self-assessments or behavioral observations of siblings.

Farber (1960) also reported increased stresses experienced by sisters of the handicapped. Farber interviewed the mothers of 233 retarded children and asked them to rate the interactions of a subsample of 78 children (all were at least 3 years old) who had a retarded sibling living at home. Farber found that for siblings who were no more than 4 years younger or older than the retarded child, 34% of the sisters and 51% of the brothers participated in activities with the retarded child on an equal basis. Siblings were more likely to participate with the retarded child on an equal basis if the retarded child was aged 7 or younger, than if the retarded child was aged 8 or older ($p \leq .01$). Mothers whose daughters interacted frequently with their retarded siblings rated their daughters higher on a role tension index (a measure of mother-sibling tension derived from mother's ratings of sibling's personality characteristics) than mothers whose daughters had little or no interaction with their retarded sibling ($p \leq .01$). Mothers' ratings of their sons' role tension were not affected by the sons' level of interaction with retarded siblings. Farber is one of the first investigators to note the significance of the phenomenon whereby the retarded child, regardless of age, tends to move in status to the position of the youngest child in the family as the retarded child grows older. This change in status requires nonhandicapped siblings to continually adjust their roles as the retarded child matures. Farber reported that sisters, but not brothers, were adversely affected by their responsibilities for the retarded child. Mothers whose daughters interacted frequently with the retarded child thought their daughters were moodier, more stubborn, and more irritable than mothers whose daughters interacted infrequently with the retarded child. Again, it should be noted that these data were based upon mothers' reports and are subject to their biases. Of particular note in Farber's study is the developmental trend that has been re-

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ported by others studying families with retarded children (Birenbaum, 1971; Wikler, 1981); siblings must continually adjust their roles as the retarded child grows older, demonstrating behavior discrepant from that of age mates.

Cleveland and Miller (1977), studying adult older siblings of mentally retarded adults, also reported differences in sibling experiences based upon sex, birth order, and family size. Brothers of the retarded children were less informed than sisters about the retarded child, and the authors speculated that this was associated with sisters' greater involvement with the retarded siblings. Sisters were closer to the retarded children than brothers, and these relationships extended from childhood to adulthood. The oldest female siblings in the families had the most responsibilities for the retarded child. Only siblings of the retarded children appeared to experience added pressures to compensate for the retarded child's deficits, and were more achievement oriented than siblings in larger families.

In contrast to the findings on birth order reported thus far, Graliker, Fishler, and Koch (1962) failed to find that older teenage siblings of retarded children had difficulty accepting their retarded brother or sister. The age gap between the handicapped child and the sibling may be a critical factor. Miller (1974) pointed out that because the siblings in Graliker et al.'s study were at least several years older than the retarded child, and the retarded children were quite young (all were 6 years old or younger), the teenagers may not have identified with their handicapped sibling; therefore, they did not find it difficult to accept the child.

The residence of the handicapped child appears to be another factor influencing the impact the child will have upon its siblings. Farber and Jenne's (1963) study of families of severely mentally retarded children revealed that boys who lived at home with a retarded sibling tended to overestimate their father's dissatisfaction with them significantly more than boys whose retarded siblings were institutionalized. Girls who lived with a retarded sibling tended to significantly underestimate their mother's dissatisfaction with them in comparison to girls with institutionalized retarded siblings. The authors hypothesized that brothers experienced fewer demands than sisters, and engaged in more activities with their peers, adopting peer attitudes and interpreting their parent's behavior, especially their father's, as reflecting disapproval. Sisters, on the other hand, had less time for peer involvement, tended to adopt their parents' viewpoint, and assumed they were fulfilling their parents' expectations. This study points out the indirect effects the handicapped child may have upon the nonhandicapped sibling's interactions with peers and with parents. Fowle (1973), studying families of institutionalized and home-reared severely retarded children, concluded that siblings of home-reared retarded children had considerably more tension than the siblings of institutionalized children. This difference was even more pronounced for the female siblings.

The Type and Severity of Handicap

Unfortunately, not enough is known about how the type and severity of the child's handicap influences the child's siblings. Such information would be useful for professionals involved with individual families. Most sibling studies have been conducted with the siblings of mentally retarded children or adults, and few report differences in sibling adjustment by degrees of retardation. Grossman (1972) did report that the community university women with mildly retarded siblings performed better in college but were more anxious than similar women with severely retarded siblings, while increased physical handicap was associated with lower anxiety and coping abilities. Breslau et al. (1981) found the handicapped child's diagnosis and disability level to be unrelated to siblings' impairment.

In one of the few studies involving siblings of physically handicapped children, McMichael (1971) asked the mothers of 37 physically handicapped children about nonhandicapped siblings' activities and social relationships and their attitudes toward the handicapped child. Interviews revealed that about 35% of the mothers felt siblings were jealous or had neurotic symptoms related to the handicapped child. Approximately 21% of siblings appeared to have moderate or severe adjustment problems. McMichael found that the main factors influencing sibling adjustment were: the severity of the handicap (the child's handicap was severe or moderately severe in all cases where siblings had severe adjustment problems); the mother's anxiety; and the emotional difficulties of the handicapped child. In another study of families of physically handicapped children, Schwirian (1976) found the presence of a preschool aged, hearing-impaired sibling did not affect the older siblings' childcare or home responsibilities, independence and privileges, or social activities. The older sibling's age and sex had a greater effect than the presence of a hearing-impaired child in families with hearing-impaired children and in a control group. Schwirian noted, however, that the siblings may experience greater demands in the future as they and their handicapped siblings mature and their siblings' hearing impairment becomes an impediment to more demanding social and verbal interactions. In another study (Barsch, 1968) of families with a blind, deaf, cerebral palsied, organically handicapped, or mentally retarded child, mothers of deaf children more frequently reported that their nonhandicapped children resented their deaf sibling than mothers of the other handicapped children. More studies on the differential impact of handicaps on siblings, as well as changes in the sibling's experience as the handicapped child matures, appear warranted.

Dynamic Variables

Sibling Interactions and Parental Norms

The studies of Grossman (1972), Breslau et al. (1981), Gath (1974), Farber (1960), and Cleveland and Miller (1977) identified siblings of handicapped children who are at risk for increased stress by virtue of their sex, birth order or age. In order to plan effective interventions for these siblings, it would seem to be useful to understand how a handicap affects sibling interactions, as well as parent-child interactions. Of particular interest to those who work with families is the difference in parents' norms for their handicapped and nonhandicapped children, since this parent-child variable will affect sibling relationships. Several studies shed light upon these latter concerns. Miller (1974) studied the activities in which nonretarded children engage with their nonretarded and their retarded siblings, the feelings they express toward their siblings, and the norms and expectations parents establish for sibling interactions. Miller interviewed 34 nonhandicapped siblings (mean age 12.6 years) of retarded children from 21 families. The average age of retarded children was 10.3 years.

Miller's respondents reported engaging in more expressive activities with their nonretarded siblings and more instrumental activities with their retarded siblings. (Expressive activities were those that were mutually satisfying and self-fulfilling; instrumental activities were associated with helping or teaching, rather than being an end in themselves.) Miller suggested these differences were due to the extra help retarded children need and the responsibility siblings experience for the retarded child's care and development. Miller found that activities that were expressive when they were performed with a nonhandicapped sibling often turned out to be instrumental when performed with the retarded sibling. For example, game playing with nonretarded siblings was considered to be expressive, while it involved teaching and helping when performed with a retarded sibling. The respondents expressed more negative affect and were more direct in expressing their feelings toward their nonhandicapped siblings. When the respondents became angry with their siblings, they were more likely to hit, tease, or call their nonretarded siblings names. They expressed their anger toward their retarded sibling by ignoring the sibling or walking away. Miller suggested that the respondents reacted less directly toward their handicapped siblings because those siblings were less likely to understand their anger. The respondents felt guilty when they became angry or hostile, and they internalized their parents' norms about how they should act. Miller's respondents reported that their parents were much less tolerant of their negative behaviors toward their retarded siblings than toward their nonretarded siblings. Siblings felt they were more likely to be punished if they did not engage in a prescribed activity with a retarded sibling than if they failed to engage in a prescribed activity with a nonretarded sibling. Again, these feelings may reflect the siblings' internalization of parents' norms. Unlike the Grossman data, Miller's data failed to reveal

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any differences in sibling relationships based upon the respondents' sex, age, or birth order. The small sample, however, did not permit meaningful multivariate analysis. Miller's data were derived from sibling interviews, and actual behavioral observations were not included.

Stoneman and Brody (1983) reported on a pilot study of five sibling pairs who were observed in a natural play sesion in their homes. All nonhandicapped children (mean age 10 years) were older than their retarded siblings (mean age 6.8 years). The older nonhandicapped siblings in each pair took on the roles of teacher and manager in the play sessions more often than the younger handicapped siblings. The confounding effects of the siblings' age and birth order (all nonhandicapped children were also first borns) make it impossible to draw any conclusions about the effect of the handicap upon role asymmetries. The study demonstrated the potential of observational research to help understand family interactions. The authors emphasized the need for data on normal control groups in order to determine whether transactions between nonhandicapped and handicapped siblings are actually different from those between nonhandicapped siblings.

The Handicapped Child's Effects on the Family's Future

Two studies offered insights into the handicapped child's influence on the family's future. Cleveland and Miller (1977) described the handicapped child's influence on siblings' life commitments, and McCullough (1981) compared parent and sibling expectations about the handicapped child's future. Although most of the nonhandicapped siblings in Cleveland and Miller's (1977) study reported that their mentally retarded younger sibling did not influence their adult life commitments, older female siblings were found to enter the helping professions more often than other siblings, and siblings who were the only nonhandicapped children in their families were more oriented towards educational achievement. Only sisters of retarded children experienced the greatest demands, and were most influenced by the retarded child in their career and family decisions.

While Miller's (1974) findings suggested that parents effectively communicate norms for their nonhandicapped children, a study by McCullough (1981) indicated that parents and their nonhandicapped children have difficulty communicating their expectations about the handicapped child's future. McCullough interviewed and administered questionnaires to parents and siblings in 23 middle and upper-middle class families of handicapped children. McCullough was especially interested in how families planned for the handicapped child's future, after parents could no longer provide primary care. All handicapped children were at least 12 years old (mean age 19.5 years), living at home, and so severely affected that they would not be able to live independently as adults. Most of the children studied were mentally retarded, and many were also physically handicapped. All nonhandicapped siblings were at least 13 years old.

McCullough asked parents and siblings what would happen to the handicapped child if the parents became unable to care for the child; whether parents and nonhandicapped siblings had discussed the future care of the handicapped child; what portion of the handicapped child's care would be provided eventually by the nonhandicapped sibling; and whether parents had made financial arrangements for the handicapped child's future? Findings indicated that the parents and siblings tended to disagree on what would happen if the parents could not care for the handicapped child. Most (60%) parents said that they had not made plans, while 60% of the siblings thought plans had been made. Sixty-eight percent of siblings thought their parents had made financial arrangements for the handicapped child's future care, while 68% of parents indicated that they had not made financial arrangements. When family members were asked whether the handicapped child would one day live with a sibling, parents were more likely to indicate this would not happen (84%) than siblings (64%).

McCullough found that although most parents and siblings agreed that the handicapped child would not be institutionalized if the parents became unable to care for the child, and although parents indicated they wanted their handicapped child to live in a family setting, parents did not indicate they wanted their handicapped child to reside with nonhandicapped siblings. Only 41% of parents thought nonhandicapped siblings would assume at least partial care of the handicapped child, while 68% of the siblings thought they would assume some responsibility for care. The picture that emerges from McCullough's study is one of parents who have not prepared their children to care for their handicapped sibling in the event of the parents' illness or death, and who have not made the financial arrangements necessary for the future of their handicapped child.

Research findings suggest that the birth of a handicapped child will affect the child's siblings as well as the parents. Siblings, like parents, must not only adjust to the birth of a handicapped brother or sister, but must continue to make adjustments throughout the family's life span. Wikler (1981) has identified predictable crises that families of the handicapped child experience as the child matures; one of these is the point at which the mentally retarded child's younger siblings begin to perform at a higher developmental level than the retarded child, one of Farber's (1960) findings with his group of siblings. Programs involving siblings in the care or education of the handicapped child must respond to the ongoing adjustments all family members must make to disruptions in normal family development. Parents of older children may need help clarifying family member responsibilities for the handicapped child in the future, while parents of younger children may need basic information to anticipate their children's questions about the handicap.

The Dynamics of Family Interactions

Future Directions for Investigation

The studies reviewed (see Table 1) identified several variables, such as sibling age and sex, and type of handicap, that influence the nonhandicapped sibling's adaptation. Several studies (Miller, 1974; Stoneman & Brody, 1983) raised important questions about the influence of the handicapped child upon family interactions, and how these interactions change over the family's life span. Just as the handicapped child's parents are influenced and affect the developing child, so too do the child's siblings influence and react to the handicapped child's behavior and development. It might be hypothesized that siblings are likely to have an indirect or minimal impact upon the newborn handicapped infant, and these early effects are likely to be mediated through the infant's parents. Siblings' contributions to the handicapped child are likely to become more significant and direct as they begin to interact more frequently with the older toddler, both in their roles as playmates and caregivers. In some families, siblings may assume responsibility for the handicapped child after the parents' illness or death.

The newborn handicapped infant, on the other hand, may exert a profound effect upon older siblings, who must learn to share their parents' attention with a new family member who requires even more care and time than newborns usually demand. Relatively little is known about how a newborn's handicap affects these family dynamics.

Future studies would benefit from a framework describing developmental changes that take place in family relations as the handicapped child and the child's siblings mature. Several frameworks for study have already been offered. Belsky (1981) proposed a comprehensive scheme for describing the family system; Belsky and Tolan's (1981) model of the development of the infant's microsystem includes the parents' marital relationship as an item of analysis, and provides a developmental perspective for studying influences on infant development. Skrtic, Summers, Brotherson, and Turnbull (1983) developed a conceptual framework describing three major family subsystems (spouse, parental, sibling) which may be studied from three perspectives (family function, structure, and cycle) to better understand family functioning.

A scheme which would include the effects of siblings upon family transactions is indicated in Figure 1. This scheme enables us to examine the quite complex ways that family members, including siblings, influence each other's behaviors and the behavior and development of the handicapped child. Beginning clockwise in the scheme (A), it can be hypothesized how the marital relationship may affect the handicapped infant's development. For example,

Table 1. Summary of Sibling Studies

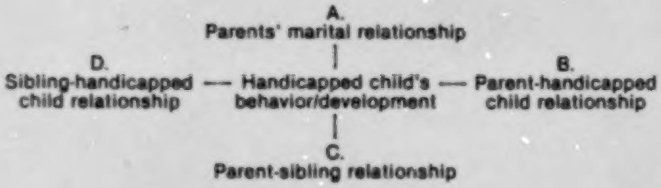
Investigator(s)	Subjects	Handicap	Variables	Study Measures	Residence of Handicapped Child
Farber, 1960	78 siblings	Mental retardation	Sex, age, birth order	Parent interviews	Home
Farber & Jenne, 1963	109 siblings (ages 11-16)	Severe mental retardation (IQ < 50) (Mean age of retarded child 8 years)	SES, religion, sex, residence of retarded child	Parent and sibling measures	74 home 35 institution
Barsch, 1968	Families of 177 handicapped children ages 4-10	Blind, deaf, cerebral palsy, Down syndrome, organic impairment. (39% severe, 61% moderate)		Parent questionnaires	
McMichael, 1971	Siblings of 37 physically handicapped children (ages 4-13)	Ranging in severity from slight to severe (40% slight, 24% moderate, 36% severe according to parent reports)	Severity of handicap, maternal anxiety, handicapped child's anxiety	Interviews with parents and teachers of handicapped children	Home (attending a day school for handicapped children)
Grossman, 1972	83 college-age siblings	17% severely/profoundly retarded, 35% moderately retarded, 48% mildly retarded, 12% severely physically handicapped, 51% moderately physically handicapped	Sex, birth order, SES	Interviews with siblings	28 institution 55 home
Graliker, Fishler, & Koch, 1962	Older teen-age siblings	Mental retardation	Age, birth order	Interviews with siblings	Home
Gath, 1972	36 school-age siblings of 22 children	Down syndrome	Sex, birth order, age	Rutter behavioral scales completed by parents and teachers	Home
	35 school-age siblings of 21 children	Cleft lip/palate			
Gath, 1974	104 families	Down syndrome			

(Continued)

Table 1. Summary of Sibling Studies—continued

Investigator(s)	Subjects	Handicap	Variables	Study Measures	Residence of Handicapped Child
Fowle, 1973	Siblings (6-17 years)	Severe mental retardation	Residence of retarded child, sex of sibling, SES	Farber Marital Integration Index, Farber Sibling Role Index	Home and institution
Miller, 1974	34 siblings (mean age 12.6)	Mental retardation (SQ < 45)	Age, sex, birth order	Sibling interviews	Home
Schwirian, 1976	77 older siblings of handicapped preschoolers	Hearing impairment	Age, sex, SES, family size, birth order, maternal age	Sibling interviews	Home
Cleveland & Miller, 1977	90 siblings (age 25 and over)	Severe/profound mental retardation	Sex, age, birth order, family size	Questionnaires completed by siblings	Mentally retarded siblings were institutionalized for average of 11 years; mean age of placement was 17 years.
Breslau, Weitzman, & Messenger, 1981	239 siblings (ages 6-18)	20% cystic fibrosis, 33% cerebral palsy, myelodysplasia, 24% multiple handicaps (ages 3-18)	Sex, age, birth order, SES	Langer's Psychiatric Screening Inventory, Level of Disability Scale, Perceived Effect on Siblings Scale (all measures completed by mothers)	Home
McCullough, 1981	25 siblings (mean age 19.6 years)	Physical or mental handicap so severe as to preclude independent living as an adult (mean age 19.5)	Age, sex, family size, birth order, SES	Interviews and questionnaires administered to parents and siblings	Home
Stoneman & Brody, 1983	5 nonhandicapped siblings (mean age 10 years) of 5 mentally retarded children (mean age 6.8 years)	Mental retardation	Role behaviors (teacher manager, playmate, verbalization)	Videotaped interactions in the home	Home

Figure 1


A.
Parents' marital relationship
D.
Sibling-handicapped child relationship
Handicapped child's behavior/development
B.
Parent-handicapped child relationship
C.
Parent-sibling relationship

Note: This scheme focuses upon the inner ring of Bronfenbrenner's (1977, 1979) ecological model which provides for the study of the infant in the context of constantly changing social, cultural, and historical influences. Analysis of any arm of this scheme requires that those environmental influences be considered; mapping changes in these sets of interactions over time likewise requires attention to changes in the individuals' environments.

parents who are experiencing marital tensions may be less sensitive to the handicapped infant's more subtle cues. Divorce or separation may significantly reduce the attention and stimulation that are available to the infant. In a reciprocal fashion, the birth of a handicapped infant may increase marital stresses, or may create new stresses. While Gath (1972) reported increased marital conflicts in families of children with Down's syndrome, Farber (1959) concluded that the parents' marital integration prior to the birth of a handicapped child was most important in determining the child's effect on the marriage. If the parents' ontogeney was examined as Belsky (1980) has suggested, we would look beyond the family's microsystem to intergenerational factors influencing the parents' behaviors and roles.

The ways in which the parent-child relationship influences the handicapped child's behavior and development is perhaps the most thoroughly investigated arm (B) of this scheme, particularly in the area of parent-infant interactions. Research on contingent interactions between mothers and their infants, and the effects of infant behaviors on parent responses and perceptions has defined the reciprocal and dynamic nature of the parent-infant relationship. For example, studies by Bell (1980) and Bristol (1979) have identified characteristics of handicapped children predicting parental stress. Als, Tronick, and Brazelton (1980) have described how parents must adapt to the blind infant's atypical behaviors to establish affective reciprocity. Infants, handicapped and nonhandicapped alike, play an active role in structuring their parent's responses to them.

Less is known about the last two arms of this scheme, the relationships between parents and siblings (C), and between siblings and the handicapped child (D), and how these affect the handicapped child. The research reviewed seems to suggest that the severity of the child's handicap may influence the degree to which the parents' relationships with the child's siblings, particularly the older sisters, will be affected. In general, it would be expected that the birth of a severely handicapped child will demand a greater emotional and financial investment from the parents, and will strain the parent-sibling relationship more than the birth of a mildly handicapped child. The birth order and sex of the handicapped child's siblings may also influence their relations with their parents. Cleveland and Miller (1977) found the retarded child's oldest sister to be at greatest risk for increased demands, and Farber (1959) also found sisters to experience more demands that may in turn affect their relationship with their parents.

Finally, Miller (1974) has addressed how handicaps affect sibling interactions. Siblings in Miller's research engaged in more instrumental activities with retarded siblings and expressed their anger less directly than with nonretarded siblings. The present authors would hypothesize that siblings who have difficulty adjusting to the child's handicap would be less likely to contribute to the handicapped child's affective development—for example, placing a handicapped child who is often socially isolated at even greater risk for social delays. In an observational study of the interactions of five blind children with their sighted siblings, Lavine (1977) described how the parents' relationship with the handicapped child may influence the relationship of the handicapped child and his siblings, as well as the parents' relationship with nonhandicapped siblings. An observational study of the interactions between a deaf 4-year-old and his younger 3-year-old hearing brother suggested that both children will be affected by the handicap—the deaf child being left out of peer and family interactions, and the hearing child not receiving the cognitive stimulation usually provided by older siblings (Kaplan & McHale, 1980).

While the scheme described in Figure 1 is more comprehensive in describing the family environment in that it acknowledges siblings' contributions in the microsystem, it fails to adequately capture the complexity of influences between family members. Others have cited the difficulty of describing the N + 3 family of infant, mother, father, and sibling (Lewis & Feiring, 1978). For example, Klein, Jorgensen, and Miller (1978) noted that in a two parent family with four children there are 147 different relational networks for analysis. Some of these networks describe interactions between family members; others describe interactions between individuals and other family relationships (e.g., the effect of parents' marital relationship upon the infant). Still others describe interactions between sets of relationships (e.g., the effect of the marital relationship upon sibling relations). A more elaborate scheme than that presented in Figure 1 would be needed to describe the reciprocal influence of parent-infant interactions as described by Clarke-Stewart (1978), as well as transitive relationships (Lewis & Feiring, 1978). For example, this scheme would provide a context for understanding how a positive mother-child and a positive mother-father relationship influences the quality of the father-child relationship (p. 62). A more elaborate model is also needed to describe how these relationships change over the family's history. In order to employ these frameworks, researchers would need to include behavioral observations as well as the family member self-reports and assessments on which previous findings are based. Stoneman and Brody (1983) have underscored the need to supplement self reports with observational methodologies that describe the context of family interactions. These methods would provide data presently unavailable on the reciprocal nature of sibling interactions. Direct observations would also avoid the problem of second person bias and recall bias that are associated with studies based on maternal reports of sibling behaviors and older siblings' reports on childhood events.

Conclusion

The research on siblings of handicapped children provides bits of information that are tempting to use in estimating the risk of sibling stress and poor adaptation. At best, when controls have been used, the data allow only comparisons of the ratio of the rate of maladaptation among siblings of handicapped children to the rate among siblings of nonhandicapped children. Those siblings who are invulnerable—those who are at high risk but who nonetheless have good outcomes—however, remain elusive. A means of getting at this information might be to expand the scope of our sibling and family studies to include the role of the family environment in family adaptation. The study of sibling adaptation has until now focused upon the role of individual characteristics and behaviors—only half of the equation describing adaptation. The information reviewed herein was derived primarily from parent or self-reports. The task now remains to study more closely the role of the sibling's family environment and to identify ecological factors as well as individual characteristics that contribute to adaptation. This ecological orientation requires methods which provide information about the family environment as well as individual family member behaviors. The observational techniques that have been used to generate hypotheses about the parent-handicapped child relationship (B in Figure 1) provide a means of generating this information. Longitudinal and observational studies of families must be undertaken to understand how children adapt to siblings' handicaps—longitudinal because siblings' experience will vary over the course of the handicapped child's development, and observational because adaptation is a function of both behavior and setting. Direct observations of family interactions can be used to validate parent, teacher and self-reports, and may generate new hypotheses about individual-environment interactions that contribute to long-term family outcomes. These data can then be used to prescribe interventions that are consistent with the roles family members assume and the settings in which they interact.

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Involving Fathers of Handicapped Infants: Translating Research into Program Goals

Donald J. Meyer
Patricia F. Vadasy
Rebecca R. Fewell
Greg Schell

While most early intervention programs for handicapped children that involve parents focus on the needs of the handicapped child's mother, the research indicates that fathers play an important role in their child's development and often need help learning how to adapt to the birth of a handicapped child and to foster the child's development. Our increasing understanding of the paternal role and the special needs of fathers enables us to suggest activities for programs to offer for fathers of handicapped young children.

■One of the most heartening social trends in contemporary America is the increasing desire of fathers to become actively involved in the lives of their infants and young children. Longitudinal studies of family styles noted that this trend was one of the most critical changes in childrearing in the 1970s (Eiduson & Weisner, 1979). Professionals in early childhood special education who endeavor to support families of handicapped children—helping them cope with chronic stresses and provide the ongoing care and attention their child will require—greet this trend with special enthusiasm. Father involvement is vital to helping families build internal networks of support that will enable them to meet the added demands of raising a handicapped child. Before special education personnel can respond to the needs of fathers of handicapped young children in an intelligent and effective manner, however, we should understand both the social factors that are influencing the father's role, and the ways in which an infant's handicap affects the interactions that take place between fathers and infants. Reviewing the research on fathers and their handicapped infants, we can identify goals for successful programs for these family members.

CHANGES IN FATHERS' ROLES

The birth of a child usually draws attention to the mother and leaves the father in the background. The mother's experience with the infant has been described in rich detail while the father is often left out of the picture until the child is older. Although most fathers have grown up with a narrow definition of their role, many men are eager to actively participate in the daily routines of child rearing (Young & Hamilton, 1979). This eagerness should not be surprising since fathers, like mothers, become attached to their infants and desire to nurture them. Early interactions are also important for the father's attachment process, although men have often had limited opportunities to spend time with their newborn infants. Recent studies suggest that fathers who are involved in their infant's early life remain active later in their child's life (Lind, 1973; Parke, Power, Tinsley, & Hymel, 1980).

Perhaps as an offshoot of the women's movement, men are increasingly dissatisfied with the narrow role model for fathering they grew up with and, consequently, are exploring new roles. Of the traditional role model, Young and Hamilton (1979) stated: "Such a role cheats fathers of being fully human and of offering a wider range of behaviors, emotions and skills to their child" (p. 141). Many men regard fatherhood as a rewarding time of personal redefinition: "Fathering often helps men clarify their values and set priorities. It may enhance their self-esteem if they manage its demands and responsibilities well" (Parke, 1981, p. 11).

The trend in fathers' increased involvement with their young children is paralleled by mothers' increasing involvement outside the home. Today, 45% of all mothers with preschool-age children work (U.S. Department of Labor, 1980). The gaps in child care available to working mothers are wide. With more mothers desiring or having to work outside the home, fathers are increasingly required to provide direct care for their children. While the death of the extended family is largely a myth (Uzoka, 1979), it appears that grandparents are less likely to be available for child care activities (Cohler & Grunebaum, 1981). As a result of these changes, fathers must be prepared to provide the necessary support.

SECOND ORDER EFFECTS OF PATERNAL ROLE CHANGES

Increased father involvement may have a beneficial effect on mothers, in addition to providing important respite. While mothers are perceived by their children as being less loving in homes where the father is not present (Crain & Stamm, 1965), mothers perform better in parenting roles when fathers are present and provide emotional support (Feiring, 1975; Pederson, Anderson, & Cain, 1977). Further, fathers' presence during mother-child interactions has been related to mothers' increased displays of interest and positive affect toward the infant. Parke and O'Leary's (1976) study of the behavior of parents of newborns revealed that mothers engaged in more exploration of their infant and smiled more when the fathers were present than when they were alone with their infants. Mothers who see themselves as one of two affectionate and caregiving parents will encourage their husband's participation and may enjoy an enhanced relationship with their infants (Sawin, 1981). The father's involvement in caregiving may provide the mother with respite and allow her to interact with her infant when she is comfortable and relaxed.

THE INFANT'S INFLUENCE ON THE FATHER

Infants are no longer assumed to be passive, helpless beings but are known to be extremely social beings who influence their parents' behavior (Brazelton, Koslowski, & Main, 1974; Condon & Sander, 1974; Stern, 1974). The literature on the infant's effects on the mother is now being supplemented by a growing body of information on the unique ways fathers are influenced by their infants.

Greenberg and Morris (1974) studied fathers' reactions to their newborn infants and used the term *engrossment* to describe the bond that develops between father and infant. More than mere involvement of a father with his infant, *engrossment* refers to that point in the father-infant relationship when the infant assumes an integral role in the father's life and the father, in turn, feels an increased sense of self-esteem and worth.

Lamb (1976) has described the bond of attachment that develops between fathers and their infants during the first few months of life. Other researchers (Field, 1978; Kotelchuck, 1976) have related the strength of the father's attachment to the father's role in caregiving activities. Investigators have found that fathers who take part in childbirth preparation are more likely to be present during labor and delivery (Parke, 1981) and those who participate in the delivery are more likely to spend time with their infants at home at three months (Levine & Block, 1980). These studies suggest that the parent's role rather than sex influences the parent's interactions with the infant. Nurturing is not biologically predetermined but develops out of the parent's early experiences with the infant.

Fathers also appear to be as adept as mothers in responding to their child's cues. Frodi, Lamb, Leavitt, and Donovan (1978) compared the responses of 48 mother-father pairs to videotapes of crying and smiling infants and found that the mothers and fathers responded similarly to the crying and smiling infants. Both mothers and fathers responded positively to the smiling infant and became distressed or irritated in response to the crying infant. The researchers pointed out that their findings contradict the notion that adult females are predisposed to be more nurturing than males.

Clarke-Stewart's (1978) longitudinal research suggests that fathers do not so much affect the social and cognitive development of their infant as they are influenced by it. The more intellectually competent the infants were at 15 months, the more likely the fathers were to talk and play with their children at 30 months. The infant, in a sense, creates its own caretaking environment by influencing the way the father responds to it. The fact that the father is influenced by the infant's qualities has implications for the interactions that occur between fathers and their handicapped infants.

THE FATHER'S INFLUENCE ON THE INFANT

In addition to providing needed respite care for mothers, competent paternal caregiving appears to influence attachment as well as the infant's cognitive/affective growth. Caregiving is an important part of the early parent-infant relationship. Lind (1973) found that fathers who were asked to undress their infant twice each day and establish eye contact with the infant for one hour each day during the first three days of life showed markedly increased paternal caregiving in the first three months of life.

Kotelchuck's (1976) study suggests that the father's involvement in caregiving was reflected in the strength of the child's attachment to the father. He observed that children who did not relate to their fathers (as indicated by children spending less than 15 seconds with fathers upon the father's arrival) were primarily from families where the father was rarely the child's caregiver. Ross, Kagan, Zelazo, and Kotelchuck (1975) found a significant relationship between a child's attachment behaviors and the number of diapers changed by the father in a week. Kotelchuck (1976) suggested that there seems to be a minimum level of paternal caregiving necessary for a relationship to exist. Lewis and Weinraub (1974) suggested that fathers need to be encouraged to assume more caregiving responsibilities to strengthen father-infant attachments.

Paternal caregiving may influence the infant's cognitive growth as well as attachment. Boys and girls who were raised primarily by their fathers scored higher on verbal abilities than children raised in traditional families in which the mothers assumed the majority of childrearing responsibilities. The childrearing fathers have been found to set higher educational and career expectations for both sons and daughters than traditional fathers who assume fewer childrearing responsibilities (Radin, 1978).

Perhaps none of the early contributions fathers make to their child's development is more significant than their role as the child's play partner. While researchers found that mothers were more likely to pick up their babies for caregiving purposes, fathers most often held their infants to play with them (Lamb, 1976). Moreover, fathers' play is clearly different in style than mothers'. Power and Parke (in press) found that fathers of 8-month-old infants engaged in significantly more physical games, such as bouncing and lifting, than mothers. Regarding the father's style, Brazelton stated: "The father adds a different dimension (than the mother), a sort of play dimension, an excitement dimension, teaching the baby about some of the ups and downs—and also teaching the baby another important thing: how to get back into control" (Collins, 1979, p. 50). Fathers' play may also have an important impact on the child's later social and cognitive development (Clarke-Stewart, 1980; Pederson & Robson, 1969). In a summary of studies on paternal characteristics, Weinraub (1979) concluded that the characteristics of the father that are most clearly related to optimal development, particularly in boys, include paternal warmth, acceptance, and involvement.

While differences between mothers' and fathers' contributions may be important, it may be the similarities in interaction styles that make a significant difference in a child's optimal development. Weinraub (1979) said that fathers are and will be increasingly important contributors to their child's development, not because they have different styles of relating to their child than mothers, but because fathers contribute as a second (one of two) *co-equal* parent in the child's social network. Fathers help fill children's many physical, emotional, and intellectual needs that are more completely met by two competent parents than by one.

THE EFFECTS OF A HANDICAPPED CHILD ON THE FATHER-INFANT INTERACTION

As one might suspect, the characteristics of the father's relationship to the child may be altered when a new father discovers that his child has a handicap. Researchers have examined the impact that a child's handicap will have upon the father. Tallman's (1965) and Farber, Jenne, and Toigo's (1960) studies suggest that fathers may have more difficulty in adjusting to the handicap than their wives, especially if the child is a son. Cummings' (1976) survey of fathers with handicapped children found that fathers were often depressed and preoccupied with their children's special needs; many men in the study felt inferior as fathers and many were dissatisfied with their children and spouses. Difficulties that fathers experience in adjusting to the birth of a handicapped infant may have second-order effects on other family members, which is important to note since several studies suggest that the father's attitude may set the pattern for the formation of other family members' attitudes in the home (Peck & Stephens, 1960; Price-Bonham & Addison, 1978). Problems of acceptance are also evident in the higher divorce rates (Tew, Lawrence, Payne, & Rawnsley, 1977) and disproportionately high desertion rates reported in several studies of fathers with handicapped children (Reed & Reed, 1965).

Fathers may not only have difficulty adjusting to the birth of a handicapped child; their attachment to the child may also be jeopardized. An infant who is developmentally delayed may be less likely to produce the same behaviors or patterns of responses that elicit social behaviors from the caregiver. Several factors may contribute to a disturbed or asynchronous parent-child interaction. Caregivers may not be able to detect when the delayed infant habituates, or loses interest. The infant may take so long to habituate that the caregiver loses interest in the interaction. Other researchers have found that parents of high-risk infants interact in a different manner with their infants than parents of nonhandicapped infants (DeVito & Goldberg, 1979; Field, 1979, 1980). The social cues that the delayed infant displays may be different or less obvious than the parent expects. Emde, Katz, and Thorpe (1978) compared the social smiles of infants with Down's syndrome and nonhandicapped infants and found that the smiles of the Down's syndrome infants were less intense and were accompanied by less motor activity. If successful parenting depends on a parent's ability to read the child's cues and interpret the child's behavior (Brazelton, Koslowski, & Main, 1974; Stern, 1974), then parents of handicapped infants who exhibit subtle or differential cues may be considered at-risk parents. Foley (1981) suggested that such parents may need help in learning to read their child's cues. The works of Fraiberg (1974) and Als, Tronick, and Brazelton (1980) illustrate the way in which parents of blind infants can be helped to read their child's nonvisual signals.

PROGRAMS FOR FATHERS AND THEIR HANDICAPPED INFANTS

A strong rationale now exists for involving fathers in programs for their handicapped young children. We now know that the birth of a handicapped infant has an impact upon the father, that it affects the attachment process and the nature of interactions the father will have with the infant, and may influence the contributions the father makes to the child's development. Cummings (1976) suggested that fathers need an opportunity to do something directly helpful for their handicapped children in order to demonstrate their love, care, and benevolent concern. Parents themselves seem to recognize this need, as demonstrated in Gallagher, Cross, and Scharfman's (1981) report on a group of parents of young handicapped children: "Across all groups there was a general agreement that there should be more father involvement with the handicapped children. The fact that this does *not* happen or *has not* happened is an area in need of investigation, but there is no doubt that it *should* happen" (p. 12).

Existing parent involvement programs, however, seem to offer few services and obtain minimal participation from fathers. In the National Institute of Mental Health (1979) overview of 24 clinical infant intervention research programs, fathers are significant in that they are never mentioned. In articles and books on the subject, parent involvement is virtually synonymous with mother involvement (Wiegerink, Hocutt, Posante-Loro, & Bristol, 1980).

It appears that the fields of early childhood and special education, like psychology, have for too long ignored the "other parent." Of the attention that psychologists have given to fathers, Parke (1981) said: "We didn't just forget fathers by accident; we ignored them on purpose because of our assumption that they were less important than mothers in influencing the developing child" (p. 4).

Now that researchers are increasingly turning their attention to fathers, it is possible to identify fathers' needs and establish goals for father-child programs. One program for fathers and their handicapped infants which has pursued the following goals is Supporting Extended Family Members (SEFAM) at the University of Washington. SEFAM, a second-year HCEEP demonstration program, is an outgrowth of a pilot Father, Infant, and Toddler Program, which has been offered at the University's Experimental Education Unit since 1978 (Delaney, Meyer, & Ward, 1980). The experience of our pilot effort and the research reviewed allowed SEFAM staff to develop program activities based on the following goals. These activities should encourage a father to:

- *Learn to read his child's cues and interpret his child's behaviors.* Because most fathers of handicapped children have little experience in child care and even less experience in interacting with a handicapped child, they often welcome information on their child's behaviors. Program staff can help fathers become more sensitive by helping them become better observers and by providing them with opportunities to talk to other fathers and share their experiences. Dickie and Carnahan's (1980) study of families taught to read and respond to children's cues revealed that training in reading and responding to infant behaviors had the biggest impact on fathers, who increased their interactions with their infants. As the research by Brazelton et al. (1974), Emde et al. (1978), Field (1980), Fraiberg (1974), and others suggests, parents of handicapped infants often need help in reading their infants' cues.
- *Develop an awareness of activities, materials, and experiences suitable to the child's correct stage of development.* Many fathers of nonhandicapped as well as handicapped children have a limited repertoire of activities they can enjoy with their child. Yet, as the research suggests, father-infant play contributes to the infant's cognitive and social development. By teaching fathers developmentally appropriate activities, games, songs, and exercises they can engage in with their infants, we can increase opportunities for playful interactions that foster attachment and enhance the child's development. Fathers often share these activities with other family members and develop their own strategies for playing with and teaching their child.
- *Practice his skills as the child's primary caregiver.* Programs that directly involve fathers with their handicapped babies allow fathers to gain and practice caregiving skills. As the research suggests, increased caregiving has implications for increasing attachment as well as for increasing the respite care that is available to mothers.
- *Learn more about the nature of the child's handicap.* Parents will have many questions when they are first informed of their child's handicap; many questions will not arise, however, until the shock has worn off and parents find themselves facing a particular developmental milestone or trying to solve a problem that they or their friends with nonhandicapped children have never experienced. Studies (Hersch, 1970; Love, 1973) and our own experience have shown that fathers are more often concerned with future problems—educational concerns, legal and economic matters—than mothers. Programs can respond to these needs by providing information on topics like special education programs, group homes, wills, and trusts.
- *Discuss his concerns with other men in a similar situation.* Fathers have fewer opportunities than mothers to share their experiences and special problems of adjusting to the birth of a handicapped child (Cummings, 1976). In order to decrease their sense of isolation and increase social supports available to them, fathers, like mothers, need an opportunity to discuss their problems with other fathers of handi-

capped children. When Leiderman asked the parents of low birth weight infants who participated in his research what kind of services they most desired, the parents indicated that they most wanted opportunities to talk to other parents who had similar experiences and who lived in their area (in discussion of Blake, Stewart, & Turcan, 1975, p. 282).

- *Develop an awareness that he, as a parent, will be his child's primary educator and advocate.* Being the parent of a handicapped child will require continuous adjustments by the child's parents. As part of that adjustment process, parents will progress from being their child's primary caregiver to becoming the child's primary educator and advocate. Bronfenbrenner's (1974) study of parent involvement in preschool programs indicated that when parents are involved in the child's educational program they can reinforce the program's effects and help sustain them when the program ends. Children who have two parents involved in their education may have their educational needs more completely met than children with only one parent involved (Weinraub, 1979). National and local policies for the education of the handicapped will influence parents' roles as advocates to ensure an adequate education for their children.
- *Explore the changing role of the father in today's society.* Today, fathers of handicapped children, like many fathers, are exploring the new roles and options available to men. Because most men lack models for the role of male caregiver, fathers interested in being nurturing parents need to gather information, ask questions, and share their thoughts about child development, discipline, eating habits, and other typical child-related concerns in a supportive environment.
- *Examine the impact of the child's handicap on the entire family structure.* The impact of the child's handicap is not limited to the child's parents. Siblings, grandparents, and other relatives all experience the handicap in unique ways (Farber & Jenne, 1963; Gayton & Walker, 1974; Grossman, 1972). Fathers who share their family's experiences with other fathers can increase each other's understanding of relatives' needs and learn how to help their family members cope with their individualized stresses.

CONCLUSION

If we wish to enhance the family's ability to cope with the challenges of raising a handicapped child, we must attempt to strengthen all of the relationships among family members, not just the mother-child relationship. We must treat both parents as a part of a family system, a system in which fathers play an increasingly dynamic role. If we wish to involve fathers with their handicapped children's lives, we may need to provide programs that directly reflect fathers' interests and concerns. The notoriously low attendance by fathers at so-called parent meetings suggests the need for programs aimed specifically at fathers. These programs may need to schedule meetings at times convenient to fathers. E. Mavis Hetherington made a telling remark about psychology that is applicable to early childhood special education: "A major reason fathers were ignored (by psychologists) was that fathers were inaccessible. To observe fathers you have to work at night and on weekends, and not many researchers like to do that" (Collins, 1979, p. 49).

Clearly, what is needed are parent involvement programs that truly seek to meet the needs, concerns, and interests of both parents. By supplementing the existing parent involvement programs that are usually geared toward mothers with programs that are tailored for fathers' needs, we may not only enhance the first- and second-order benefits previously described, but also acknowledge that both parents are integral parts of the handicapped child's family system.

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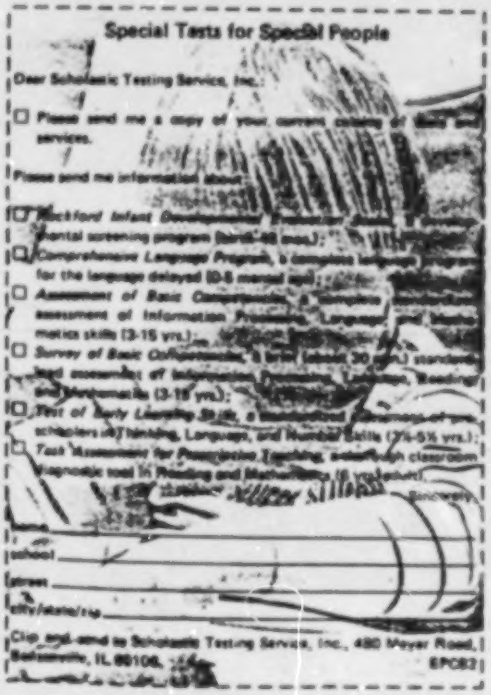

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Involved Parents: Characteristics and Resources of Fathers and Mothers of Young Handicapped Children

Patricia F. Vadasy
Rebecca R. Fewell
Donald J. Meyer
Greg Schell
Mark T. Greenberg

Who are the families who choose to participate in an early intervention program tailored to meet the needs of traditionally underserved members of the young handicapped child's family? In an HCEEP project for fathers and their infants and toddlers, both parents completed a set of measures that provided demographic information, as well as data in the following areas: paternal information needs; family responsibilities; parent levels of depression; personal time; organized group affiliation; and satisfaction with their present situations. Fathers who participated in the pilot program for the project were compared to newly enrolled fathers along these variables, and husbands' and wives' responses were compared. Fathers who had been in the pilot program were less depressed, had more positive feelings about their interactions with their children, and had greater access to social supports than the newly enrolled fathers. Predisposing variables associated with families' program participation are discussed.

■ The birth of a handicapped child will have longitudinal effects on all family members that cannot be adequately measured at any single point in time. The father and siblings, as well as the child's mother, will have unique reactions to the child's initial diagnosis, and will experience the child's handicap within their family roles as the child matures. The child will influence persons and events within the immediate family environment as well as beyond, in the family's neighborhood, extended family, school, and community. Bronfenbrenner's rationale for ecologically based interventions for families of handicapped children is based in part on the recognition that resources at each level of the family's environment contribute to the family's adaptation and to the child's development. Bronfenbrenner (1975) described the ecological intervention as resulting in "changes in the context in which the family lives that enable the family as a whole to exercise the functions necessary for the child's development" (p. 468). One of the primary goals of an ecological intervention for families of young handicapped children will be to improve family functioning at a particular point in time. A successful program will increase the ability of family members to cope effectively with the stresses resulting from the child's handicap.

The actual and perceived stress each family member experiences will be a function of several variables. First, each member's reactions to the birth or diagnosis of a handicapped child will influence the stress the

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family experiences. The family's income and education will also have a bearing on their ability to cope with stress. The family's coping will be influenced by the information, professional advice, support, and counseling they receive. Their access to familial and extrafamilial social supports that can aid in solving problems and adapting to new demands will also influence their level of stress. Research suggests that these variables may act as buffers to mediate the effects of stressful events. For example, income has been found to be inversely related to stress (Dohrenwend & Dohrenwend, 1969), and individuals with access to social supports seem to have a lower susceptibility to stress and illness than more isolated individuals (Cassel, 1974; Lin, Simeone, Ensel, & Kuo, 1979), although further study of the relationships between stress and support is needed (Thoits, 1982).

Finally, the individual's belief systems influence the way potentially stressful experiences are perceived (Folkman, Schaefer, & Lazarus, 1979). For example, persons who feel they can control their situation are less likely to experience stress than persons who feel powerless to act and effect changes (Sarason, Johnson, & Siegel, 1978). One of the challenges that researchers face is to identify factors that mediate stress in family environments at particular points in the family's life span. This information is needed to provide optimally effective ecological interventions.

In the meantime, many programs for handicapped children and their families attempt to alter factors that are amenable to intervention, for example, by providing parents with information, supplemental income, or access to a support group. A growing body of research on families of handicapped children has identified family characteristics that are associated with successful coping (Bristol, 1979; Friedrich, 1979; McCubbin, Joy, Cauble, Comeau, Patterson, & Needle, 1980; Strom, Rees, Slaughter, & Wurster, 1981). In our first year's work in a program for fathers of handicapped young children, we have attempted both to provide services that are likely to reduce families' stress, as well as to identify the characteristics of families who are coping successfully with the stresses of raising a young child with a handicap.

THE SEFAM PROGRAM

Supporting Extended Family Members (SEFAM) is a third-year Handicapped Children's Early Education Program (HCEEP) project that is being conducted at the Experimental Education Unit of the Child Development and Mental Retardation Center at the University of Washington. Based upon a pilot program for fathers and infants that has been offered at the University of Washington since 1978, SEFAM is designed to help fathers adjust to their child's handicap and become effective caregivers and advocates for their child.

Fathers and their children meet with the program leaders, two male teachers with master's degrees in early childhood special education, for two hours every Saturday morning. During this time the fathers learn activities and games they can enjoy with their children, share their concerns with other fathers, and learn how to help their family cope effectively with the responsibilities of caring for and educating a child with special needs. They have an opportunity to meet and get to know other fathers with similar concerns, and to ask questions of the program leaders, the other parents, and the guest speakers who are invited to discuss topics of group concern. The meetings offer the fathers a regular source of social support that can reduce their feelings of isolation, and the mothers are provided a brief respite from childcare responsibilities. In the second year of SEFAM (1982-83), staff added a series of workshops for the young siblings of handicapped children, and in the third year the program will also serve the children's grandparents, aunts, uncles, and other relatives.

At the outset of our program, we set out to collect data to define the person × environment match that optimizes development in families with handicapped children. Many of the domains we chose to focus on were suggested by Folkman et al.'s (1979) model of coping resources that mediate stress. These researchers identified five types of resources that may facilitate the family's adaptation to the handicapped child: health/energy/morale; problem-solving skills; social networks; utilitarian resources; general and specific beliefs. Friedrich, Greenberg, and Crnic (in press) have shown the utility of applying this model to the study of handicapped children

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and their families. We proposed to monitor changes in variables in nine domains for the fathers, and in three domains for the mothers (Table 1). At the beginning of our first year of demonstration funding (1981-82), we identified a set of 10 measures that we asked the fathers in the SEFAM program to complete. Their wives were also asked to complete four measures that would provide data on the impact of the fathers' participation in SEFAM upon their wives. Twenty-three fathers and their wives completed the following pretest measures:

Parent Needs Inventory (Robinson & DeRosa, 1980)

Inventory of Home Stimulation (Caldwell, 1970)

*Family Environment Scale (Moos, 1974)

*Beck Depression Inventory (Beck, Ward, Mendelson, Mock, & Erbaugh, 1961)

TABLE 1
Parent Variables Assessed

Name of Instrument	*Father's Scale*										*Mother's Scale*		
	Father's Behaviors	Child's Behaviors	Interaction Between Father and Child	Factors in Child's Home Environment	Father's Knowledge of Community Resources	Father's Stress Level	Father's Depression Level	Knowledge of Child Development	Support Systems		Mother's Stress Level	Mother's Depression Level	Support Systems
*Parent Needs Inventory					X	X		X					
*H.O.M.E.	X		X	X									
*Interviewer Rating of Family and Child Adjustment			X	X									
*Assessment of Fathering Behaviors	X		X						X				
*Teaching Scale	X	X	X	X									
*+-Questionnaire on Resources and Stress		X				X	X				X	X	
+-Inventory of Parent's Experiences									X				X
+-Beck Depression Inventory							X					X	
+-Family Environment Scale				X		X			X		X		X
-Individualizing Parent Involvement					X								
-Demographic Information Form													
-Personal Information Form													

Legend:
* = administered in home visit
− = parents fill out and return
+ = both mother and father complete form

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Assessment of Fathering Behaviors (Murphy, 1979)
Interviewer Ratings of Family and Child Adjustment (Greenberg, 1981)
*Questionnaire on Stress and Resources–Revised (Holroyd, 1973; 54-item version adapted by Friedrich, Greenberg, & Crnic, 1983)
Individualizing Parent Involvement (Meyer & Schell, 1981)
*Inventory of Parent's Experiences (Crnic, Ragozin, Greenberg, & Robinson, 1981)
SEFAM Demographic Form

Posttesting of all Year 1 families was completed in Spring, 1983, and all families will be assessed yearly thereafter.

Following is a profile, drawn from pretest data, of the families who participated in the first year of SEFAM demonstration and longitudinal research. These descriptive data will introduce the reader to a small, self-selected group of families who experience many of the stresses and demands shared by all families with a handicapped young child. It is also a group that is characterized by strong personal support networks that will be examined closely in our longitudinal research.

The Children

The children in the Year 1 SEFAM program ranged in age from 7 to 48 months (mean age 26 months). There were 13 males and 10 females. Eleven of the children were firstborns. Of the total of 23 children, 13 were identified as having Down's syndrome; 1 each as having microcephaly, arthrogryposis, cerebral palsy/severe mental retardation, infant spasm syndrome, trisomy 10 Q, Williams syndrome, hemiplegia, and chromosomal disorder/cleft lip and palate; and 2 as having unknown developmental delay.

The large number of children with Down's syndrome is accounted for by the many families who are drawn to the Experimental Education Unit's Model Preschool, where the Program for Children with Down's Syndrome and Other Developmental Delays was developed in 1969. When we asked parents to describe secondary health problems and physical impairments that their children experienced, 70% reported a history of ear infections, and 44% reported tongue protrusion, two conditions that are often found in children with Down's syndrome.

Parents were asked when and how they were told of their child's handicap. Seventy percent reported they were told at the time of the child's delivery or prior to discharge. In 57% of families, the diagnosis was conveyed by a pediatrician, and in 26% of families another physician presented the information.

In 57% of families, both parents were present when the diagnosis was given; one father (4%) and 39% of mothers were alone when they received the diagnosis. In responding to their child's medical needs, 83% of mothers had the primary responsibility for contacting medical and health specialists; 13% of families shared this responsibility equally between parents. Only one father (4%) reported that this was primarily his responsibility.

Parents provided information about the regular early intervention programs in which their children were served. All children had been enrolled in at least one infant program (mean 2.7), and some of the children had attended up to four infant programs (13%). Most of the families (78%) reported that their child's attendance in these programs was good (between 80% and 100%). These data reflect the wide range of programs available for young handicapped children and their families in the greater Seattle area, and the parents' relatively high level of commitment to those programs.

The Parents

Of the 23 families who completed Year 1 measures, seven had participated in the pilot program for periods of from 1 to 3 years. The families were predominantly white, middle class, and well educated. Participating parents included one Oriental father, one American Indian mother, and one Hispanic mother. Half of the families lived in urban areas with populations of at least 50,000. Thirty percent of parents had a bachelor's degree; 35% of fathers and 17% of mothers had completed some graduate work. The majority (78%) of fathers and 23% of mothers were employed in professional occupations. All but two of the fathers were employed full time. Only one mother (4%) was employed full time, and six

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*Mothers completed these 4 measures.

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TABLE 2
Family Income Data

Combined Gross Income	*N*	*Adjusted Frequency*	*Relative Frequency*
$30,000 and above	6	40%	26%
20-29,000	5	33	22
15-19,000	1	7	4
11-14,000	1	7	4
less than $10,000	2	13	9
missing	8	—	35
Total	23	100%	100%

(26%) were employed part-time. Not surprisingly, the employment rates for the SEFAM mothers are much lower than the rates for mothers in the general population, where 48% of all married women with a husband present in the home and children under 6 years old are in the labor force (Hayghe, 1982). Forty percent (adjusted frequency) of families had combined gross incomes of $30,000 or above, and 33% were in the $20,000-$29,000 range (Table 2).

While several studies suggest that the parents of handicapped children are at risk for divorce and marital stress (Gallagher, Cross, & Scharfman, 1981; Gath, 1978; Love, 1973; Price-Bonham & Addison, 1978), all of the SEFAM families are intact, and the majority appear to be quite stable. Ninety-six percent of parents said that they expected their relationship with their spouse to continue.

Parental Concerns

One of the measures used primarily to help plan guest speaker presentations and topics for group discussions also provided data on paternal concerns. Table 3 describes the percentage of fathers who indicated they had questions about these specific concerns.

These data support the findings of others (Hersch, 1970; Love, 1973) that fathers of handicapped children have a strong interest in the child's future, while mothers are usually more involved in the child's immediate care. The data also reflect a phenomenon that our program facilitators have observed over the course of the program years. Discussions during the SEFAM meetings at the beginning of each program year often focus on "safe" topics, such as legal concerns or educational programs. These general topics are often removed from the fathers' more immediate and personal concerns. As the fathers begin to feel more comfortable and familiar with the leaders and the group members, they begin to share more personal concerns and worries. As noted subsequently, the fathers' relatively low level of interest (35%) in information regarding religious programs for their child is not a measure of their disinterest in these programs, but seems to reflect families' active involvement in religious groups.

Comparison of Baseline Data

Parent fatigue and mood

Several instruments were used to assess the child's impact on each of the parents and on

TABLE 3
Paternal Concerns

Concern	%
Programs for the older child	91
Child's future	90
Special education laws	87
Program availability	86
Tax information	83
Child development	83
Advocacy groups	74
Sex education	65
Public reaction	63
Nutrition	61
Specific handicaps	57
Respite care	44
Religious programs for child	35

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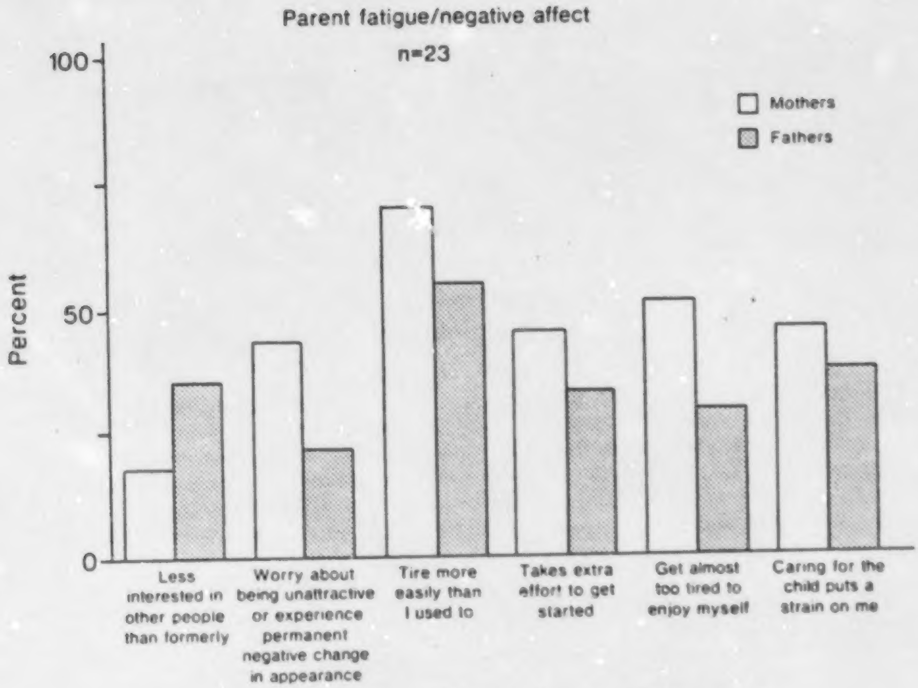

FIGURE 1. Parent fatigue/negative affect.

family activities. The literature indicates that families of handicapped children often experience increased caretaking demands which result in fatigue, reduced time for individual family members, and emotional problems, including depression (Farber, 1960; Gallagher et al., 1981; Gath, 1978; Hewett, 1970; Hunt, 1973; McMichael, 1971; Pless & Satterwhite, 1975). The Beck Depression Inventory was used to assess parents' mood. Thirty-five percent of fathers and 17% of mothers reported that they were less interested in other people than they used to be (Figure 1). Mothers (43%) reported more frequently that they experienced negative changes in their appearance than the fathers (22%). Thirty-five percent of the fathers and 44% of mothers said that it took more effort to get started at doing things than previously. Seventy percent of mothers and 57% of fathers tired more easily than they used to. These data on the Beck were supported by parents' responses to several items on the Questionnaire on Resources and Stress–Revised, where 52% of mothers said they were too tired to enjoy themselves, compared to 30% of fathers. Forty-four percent of mothers and 39% of fathers reported that caring for the index child was a strain.

Parents' childcare and housework responsibilities

Because mothers are usually primarily responsible for childcare, we wanted to know how much time the mothers spent with the index child as well as with other children in the family, and their satisfaction with the situation. While the majority of mothers (65%) reported that they spent over 5 hours daily with the index child, only 27% of mothers said they spent more than five hours with the other children in the family (Figure 2). In most families the other children were older than the handicapped child, and the average age of other siblings was 5 years. Thirteen percent of mothers expressed dissatisfaction with the amount of time spent with the handicapped child, and 27% said they were dissatisfied with the amount of time they spent with other children in the family.

Parental, particularly maternal, fatigue is

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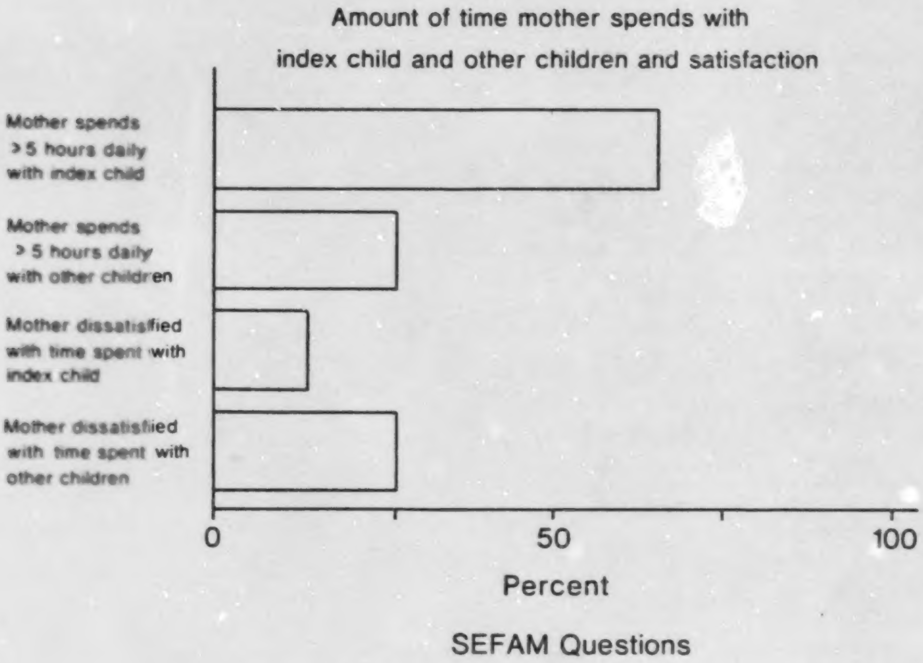

FIGURE 2. Amount of time mother spends with children.

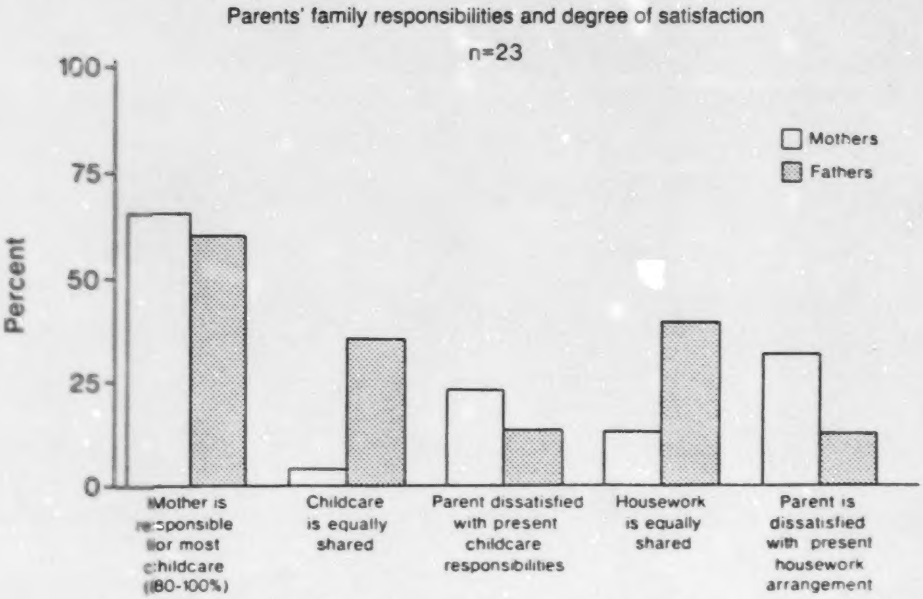

FIGURE 3. Parents' family responsibilities and degree of satisfaction.

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not surprising when we examine how childcare is divided between parents, and how much personal time is available to each parent daily. Mothers and fathers disagreed somewhat when asked who was responsible for most of the childcare. Although 61% of fathers and 57% of mothers agreed that the mothers were responsible for most childcare, 35% of fathers but only 4% of mothers said that childcare was shared equally (Figure 3). Thirteen percent of fathers and 23% of mothers said they were dissatisfied with the present division of childcare. Parents also disagreed when they were asked to describe housework responsibilities. Thirty-nine percent of fathers but only 13% of mothers said that housework was shared equally. Again, 13% of fathers and 32% of mothers were dissatisfied with the present arrangement.

Personal respite

Respite care is often a pressing need for parents of young handicapped children. In order to estimate the time demands parents experienced, we asked them to estimate the amount of time they had for themselves each day (Figure 4). Twenty-six percent of fathers and 13% of mothers said they had less than ½ hour to themselves each day. Thirty-five percent of fathers and 57% of mothers reported they had ½ to 1 hour per day to themselves. Over 60% of fathers and 70% of mothers had no more than 1 hour to themselves per day. About 44% of both parents were satisfied with the amount of time they had to themselves each day.

Social, cultural, religious involvement

In light of the time demands the parents experienced, it is not surprising to find that their social lives were quite restricted (Figure 4). Ninety-two percent of parents reported that they spend most weekends and evenings at home. While we would expect that parents of young infants and toddlers would have to restrict their social activities, we might expect professional and upper-middle class families to lead somewhat more active social lives than a group with greater economic constraints, particularly since 70% of mothers and 57% of fathers expressed an interest in cultural activities. Yet about 90% of parents said they rarely attended lectures, plays, or concerts.

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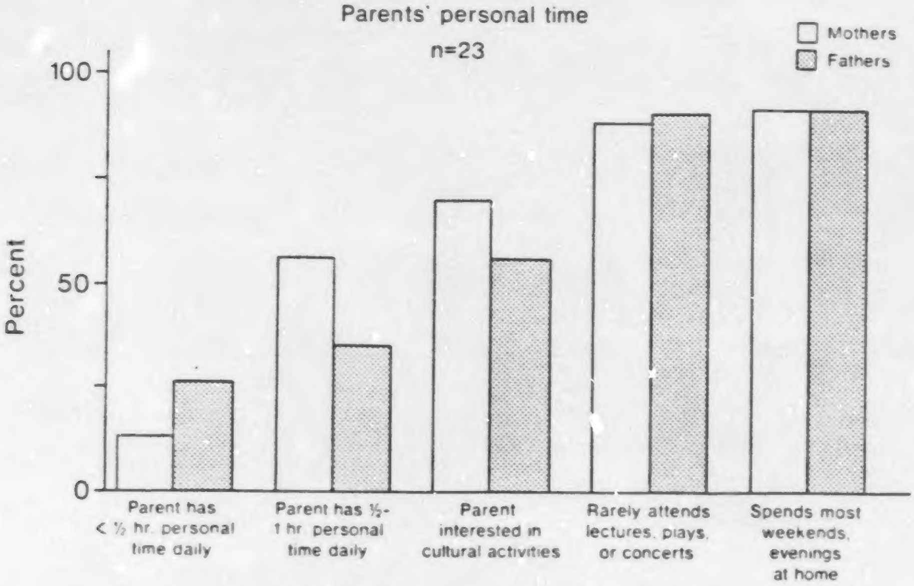
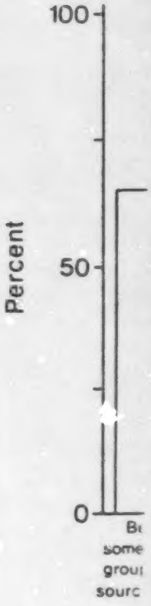


FIGURE 4. Parents' personal time.



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tural activities, they did find time to belong to community and church groups. Seventy-eight percent of fathers and 65% of mothers reported involvement in an organized group and in an organized religion (Figure 5). Seventy-six percent of mothers and 87% of fathers were satisfied with the support they received from the groups they belonged to. A striking characteristic of the SEFAM families is the role of religion in their lives (Figure 5), particularly in a region of the country characterized by low levels of church membership. Ninety-six percent of mothers and 87% of fathers reported they believed in heaven and hell; 74% of the families pray together; and 64% of fathers and 61% of mothers said the family discussed the religious meaning of holidays. Ninety-one percent of parents said their family experienced feelings of togetherness. Eighty-three percent of mothers and 91% of fathers were satisfied with their involvement in organized religion. Pearson product-moment correlation coefficients revealed a high negative correlation between fathers' satisfaction with their religious involvement and their depression, particularly their sadness, sense of failure, and guilt ($p < .001$).

EFFECTS OF PILOT PROGRAM PARTICIPATION

An adaptation of Folkman et al.'s (1979) model of coping will be used to study changes in the families over time. Although we do not yet have posttest data that will enable us to look at changes in the families over the first year of the demonstration program, we have examined the pretest data to see if there are differences between parents who have been involved in the pilot program and parents who were new to the program at the time of pretest. As mentioned earlier, at the time of pretest seven fathers had been in the pilot program for 1 to 3 years, and 16 fathers had just entered the program. Pretest results showed differences between these two groups in several areas: depression, father-child interaction, and support systems. The fathers who had been in the pilot program were less depressed in terms of being less tired ($p < .05$) and feeling less unattrac-

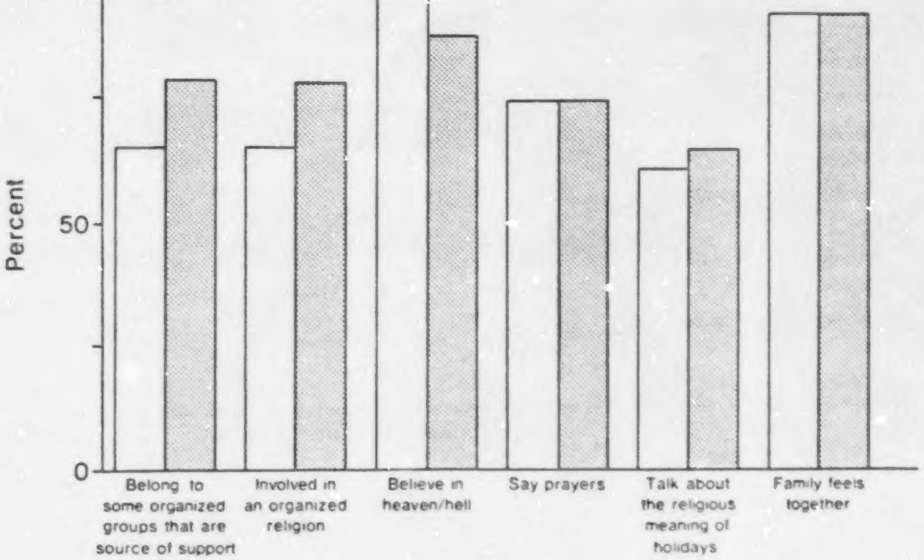

FIGURE 5. Organized group and religious affiliation.

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tive ($p < .05$) than the newly enrolled fathers (Table 4). Comparison of several variables describing fathers' feelings about and interactions with their children showed that pilot fathers were less likely than newly enrolled fathers to have mixed feelings or be irritated by their children ($p < .10$), and their children demonstrated higher clarity of cues ($p < .01$).

The two groups also differed in their access to and need for social supports. Pilot fathers had less need to talk to someone about their children ($p < .02$), access to more organized groups ($p < .05$), more telephone contacts ($p < .02$), and more people available to them when they were upset ($p < .02$) than newly enrolled fathers.

Finally, the wives of the pilot fathers reported a lower sense of failure ($p < .10$), but a greater degree of pessimism ($p < .05$) than wives of newly enrolled fathers.

These pilot data are tentative and do not take into account length of the fathers' involvement, the effects of the parents' or children's ages, or other variables to be examined closely in posttest comparisons.

CONCLUSION

At first glance, this research on stress and coping in a sample of intact, economically secure, community- and religiously-oriented families appears doomed by the lack of variance in a biased sample. At pretest none of the SEFAM parents were separated or divorced, nor did they exhibit signs of severe stress, family discord, or depression. However, our clearly biased sample may provide important information about the family characteristics that mitigate the stress of raising a handicapped child.

Many families of handicapped children experience stress in the form of increased expenses for medical visits, health insurance, special equipment, and lost income to nonworking mothers. Two of the major issues that the Carnegie Council on Children highlighted in their analysis of childhood disabilities concern parents' health insurance and disability insurance needs. The authors recommended that a national health insurance and disability insurance be available to

TABLE 4

Effect of Parents' Status in Pilot Program on Selected Variables

Variable	*Pilot Fathers (n = 7)*	*Newly Enrolled Fathers (n = 16)*	*t*	*df*
	Mean			
Tire more easily than usual	.286	.813	−2.30*	13
Feel more unattractive	0	.44	−2.41*	15
Desire more people to talk to about index child	1.43	3.44	−2.52**	21
Number of phone calls with friends/family	3.57	2.56	2.89**	11
Number of people available to talk to when upset/angry	3.43	2.40	2.48**	16
Access to organized groups for support	2.14	1.75	2.17*	14
Child's clarity of cues	9.43	8.13	3.15***	17

Variable	*Pilot Mothers (n = 7)*	*Newly Enrolled Mothers (n = 14)*	*t*	*df*
Pessimism	3.37	2.07	2.46*	15

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help families defray both the direct medical expenses and the hidden costs that they incur in caring for their child (Gliedman & Roth, 1980). With the large proportion (48%) of SEFAM families falling into combined gross income categories of at least $20,000, and with 21 fathers (91%) employed full time, the families may be at reduced risk for experiencing these economic burdens.

Several other demographic characteristics may explain why the SEFAM families are at reduced risk for the stresses reported in the literature. The parents' average age is 33, and they may not experience the stresses that a younger group of parents would experience. Most families (83%) are fairly small (1-3 children), and small family size may account for reduced stress because parents do not experience the demands on their time that are experienced by parents with larger families. As noted earlier, many of the SEFAM mothers are not employed outside the home and are not required to divide their time between their job and their childcare and housework responsibilities. The fact that the majority of mothers are not working outside the home also reduces the demands their husbands would otherwise experience if they had to share a greater proportion of childcare and housework with their working wives. Education is another resource for these families, with 65% of fathers and 48% of mothers having completed at least four years of college.

Along with these environmental factors which may mitigate family stress in our sample, we find evidence of what has been described as a sense of coherence (Antonovsky, 1979), which Werner and Smith (1982) attributed to the success of the "resilient" children in their longitudinal Kauai study of at-risk children. About one-fourth of our families reported a previous family history of handicaps, which may provide them with experience and resources that families without a handicapped family member do not possess. In terms of personal resources, access to religious and organized groups also stands out quite prominently in our group of families. Even prior to their involvement in the SEFAM program, these families sought out support from various organized groups and demonstrated the ability to use social supports, which may have helped them access a program like SEFAM. Their education, income, and previous group affiliations may serve as enabling or predisposing factors that facilitate their access to intervention (Anderson & Newman, 1973).

The high level of social competence and cohesion the participating families demonstrate raises a particularly difficult question—how do we attract families who do not have these characteristics into the program? Our comparison of fathers who participated in the pilot program and fathers new to the program suggests that fathers in the program may experience reduced depression and increased satisfaction with their children compared to fathers who have not experienced a similar support group. The pretest data suggest that mothers may also benefit from their husbands' participation. These are trends we will need to study during and after the families' involvement in the demonstration program.

Longitudinal study of this nature is warranted not only to identify effects of program participation but also to determine how families' needs change over the course of the child's development. In the first year of the program, SEFAM served fathers of children up to 2 years old. The children's age may contribute to the low levels of stress their parents are experiencing, and it may be that parents' feelings and needs will change as their children approach developmental milestones and fail to meet increasing parental expectations. These questions will be addressed in our longitudinal study of coping and stress. Focus upon child and parent characteristics, as well as upon the families' personal and social resources, may help us better define the characteristics of resilient families who cope successfully with the stresses reported in the literature on families of handicapped children.

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FATHERS OF CHILDREN WITH HANDICAPS:
DEVELOPMENTAL TRENDS IN FATHERS' EXPERIENCES
OVER THE FAMILY LIFE CYCLE

DONALD J. MEYER

IN: FAMILIES OF HANDICAPPED CHILDREN:
NEEDS AND SUPPORTS ACROSS THE LIFESPAN

Prepublication Draft

Fathers of Children with Handicaps:
Developmental Trends in Fathers' Experiences Over the Child's Lifespan

Donald J. Meyer

While an increasing amount of information is available about the father's reaction and initial adaptation to the diagnosis of his child's disability, less is known about the effects of the child's handicap on the father as the child grows into adulthood. This chapter will attempt to explore the changing effects of the child's handicap on the father over the child's lifespan. After reviewing the research literature and personal accounts by fathers, implications for providing services and supports to meet fathers' changing needs will be discussed.

INTRODUCTION

> I thought about Noah and how he would never recover and how we would never get over him. He's an affliction here to stay, one that continually unfolds (Greenfeld, 1979b, p. 52).

In his sensitive and often painfully honest books about his severely handicapped son, Josh Greenfeld allows the reader to witness the impact of his son's handicap from the time it was first suspected, through the initial frustrations of obtaining an accurate diagnosis and adequate educational programs, to the sorrow of Noah's still slow, still erratic behavior in his tenth year. What Greenfeld describes in his often angry books runs counter to what family theorists have thought about parents of children with handicaps.

The early literature on parent reactions (American Medical Association, 1964; Menolascino, 1977) suggested that parents, confronted by the "novelty shock" of the diagnosis, proceeded through predictable stages leading to a final resolution. Miller (1968) suggested that parents go through stages of disintegration, characterized by shock, denial, and disorganization; adjustment, when parents alternately accept and deny the existence of the handicap; and re-integration, when parents pull themselves back together and begin to function more effectively and realistically. While these stages are not totally inaccurate, they are based on the assumption that following reintegration, parents re-assume a life that, while it is not entirely normal, is not unduly stressful.

Greenfeld's experiences more closely resemble the emerging view of parents' adaptation to a child's disability. This view holds that although parents regain equilibrium following the initial shock, their adjustment may be temporary: parents will be subject to chronic, stressful reminders of the tragedy of the child's disability throughout the child's lifespan (Olshansky, 1962; Wikler, 1981). Wikler, Wasow, and Hatfield (1981) interviewed parents and social workers and found that 67 percent believed that parents experience chronic sorrow across developmental stages. Further, the social workers tended to overestimate the impact of the disability in the early years and underestimate the stress parents experience later in the lifecycle.

Wikler (1981) contends that these stresses occur "when a discrepancy emerges between what parents expect of a child's development and of parenting as opposed to what actually takes place when rearing a mentally retarded child" (pp. 283-284). She notes that some of these stresses are related to hardships unique to mental disability, such as stigmatized social interactions and a prolonged burden of care. Others are typical parental responses to retardation such as grief and a need for specific information. Wikler's concept of reoccurring crises and stress will be further discussed in context in the remainder of the chapter.

Some family theorists, such as Duvall (1962) have observed that families, like individuals, proceed through a life cycle consisting of overlapping stages. Just as an individual grows, develops, matures, and ages, undergoing continual change and readjustment throughout his or her life, families also have a life cycle. They are "born"; they grow, change, and age. Events, such as divorce, desertion, or death will profoundly affect the family life cycle. However, few changes in the family will have a greater effect on the life cycle than the birth of a disabled child. The remainder of this chapter will explore the impact of the child's disability on the family's life cycle, especially as it pertains to the father.

While there has been an explosion of research on fathers in the past few years, still relatively little is known about fathers of handicapped children. Mothers of handicapped children have been the traditional focus of research. Most studies of fathers focus on the father's reaction to the diagnosis or his initial adaptation. Much less is known about the effects of the child's handicap on the father as the child grows into adulthood. In the sections that follow, chapters, articles, and books written by fathers themselves will be reviewed to fill in the void in the research literature. Caution is advised when making inferences from the research and accounts presented: intervening variables such as disability type and support measures will allow for a wide range of experiences among fathers. This chapter will focus primarily on fathers of children with mental retardation. However, other factors in addition to the type of handicap will influence a father's experiences. For example, the experience of a father with a passive child with Down syndrome may be quite different from the experience of a father whose child is also physically disabled or has aggressive or autistic behaviors. Similarly, the experience of a father whose marriage is sound and whose employment is secure prior to the diagnosis of the child's handicap may differ greatly from the experience of a father whose marriage is unstable and who is unemployed at the time of diagnosis. Intervening variables and mediating factors will be discussed later in the chapter.

The stages in the family lifecycle referred to in this chapter are those described by Duvall (1962). As we shall see, the stages in the family life cycle will be markedly different for fathers and families with handicapped children. In some cases, these stages may be non-existent.

STAGE ONE: THE BEGINNING FAMILY

The initial stage in the family life cycle typically begins when the couple marries, and it continues until the woman becomes pregnant. Like all stages, this stage is subject to variation and exception. For instance, if the woman is pregnant at the time of the marriage, the "developmental tasks" of this stage will include those of the following stage, the expectant couple.

According to Duvall (1962) the primary developmental tasks for the new couple are to adjust to one another and their new relationships. These primary adjustments will likely involve many secondary adjustments in order to fulfill basic requirements for housing; finances; sexual, emotional, and intellectual communication; division of domestic responsibilities; establishing relationships both as individuals and as a couple; and developing a compatible philosophy of life.

Obviously, the experiences of couples who later have a handicapped child will be much the same in this stage as the experiences of other couples. It is during this time, however, that a couple will either succeed or fail at developing a relationship that can withstand the test of a child's handicap.

Gath (1977) suggested that the stability of the marital relationship prior to birth of the special child may mediate the effects of the child's handicap on the family. She studied 30 families with children who have Down syndrome and an equal number of matched controls. Negative findings, such as marital breakdown or severe marital disharmony, were found in 30 percent of the index families and in none of the control families. Severe tension, high hostility, or marked lack of warmth between husband and wife were noted in several of the families with handicapped children. It is interesting to note that although negative measures were higher in the parents of children with

Down syndrome, the positive measure were also higher for this group. Gath observes that, despite their grief, the parents of almost half of the children with Down syndrome involved in the study felt that their marriage was strengthened after the birth of the handicapped child.

Studies by Gath and others (Farber, 1972) suggest that the presence of a handicapped child can be a critical factor in dissolving a marriage in which there are problems or instability prior to the child's birth and, conversely, can be a unifying factor for parents who enjoyed a strong, close marriage prior to the birth of the handicapped child.

STAGE TWO: THE EXPECTANT COUPLE

Barring amniocentesis, the expectant couple, like the beginning family, will be unaware of their future child's handicap. Duvall (1962) notes that it is during this time that the expectant father will address the developmental tasks of planning for the child's arrival; learning what it means to become a father; and supporting his wife through pregnancy and childbirth.

Brazelton (1979) suggests that expectant parents also engage in another less obvious, yet important task: preparation for the possibility of a handicapped child. Brazelton's colleagues conducted psychoanalytic interviews weekly with expectant mothers and monthly with fathers during the last trimester of pregnancy. The purpose of the interviews was to ascertain "what kind of people they were" in hopes of predicting "what kinds of parents" they would become. When parents were given a chance to share their innermost thoughts during the interviews, Brazelton's colleagues discovered the expectant parents to be filled with inner turmoil. Many doubted their abilities to be an effective parent, and expressed ambivalence about wanting the child, and fears about bearing a damaged child. The expectant parents' fears and concerns were so pronounced that Brazelton's colleagues predicted that all the fathers would become paranoid schizophrenics and all the mothers would be severely depressed!

Of course, follow-up visits showed both fathers and mothers to be healthy parents. While the interviews clearly failed to show predictive validity, Brazelton suggests they point out an important function of the expectant parents' thinking: the couple's anxiety, ambivalence, and fears prepare them to cope with any child they may bear - active, passive, or handicapped. By anticipating the possibility of a handicapped child, parents rehearse some coping strategies and are somewhat better prepared for the shock that accompanies the birth of a handicapped child.

Couples who receive the results of amniocentesis may need to make their initial adjustment to their child's confirmed handicap during this stage. Improved medical technology has made amniocentesis a relatively safe and accepted means of diagnosing over 100 diseases. For many at-risk expectant parents, amniocentesis can assure them that their child does not have a genetic defect.

But what if the fetus is genetically defective? According to researchers, families may pay a psychiatric price when they elect a therapeutic abortion upon being told their child is "genetically defective." While women who undergo an elective abortion often experience emotional and psychological effects, undergoing a therapeutic abortion for genetic defects is more traumatic for several reasons. Women who choose elective abortions for psychosocial or socioeconomic reasons during the first trimester of pregnancy appear to be at minimal risk for negative long-term psychological sequelae (Blumberg and Golbus, 1975). These pregnancies are usually unplanned and the abortions are performed early in the pregnancy, before the onset of quickening.

Therapeutic abortions, on the other hand, are usually performed on mothers who had welcomed the pregnancy. Compounding the trauma of terminating a desired pregnancy is the fact that having anmiocentesis makes a second- trimester abortion necessary. Amniocentesis to detect hereditary disease or congenital defects is performed at 14 or 16 weeks of fetal gestation (U.S. Department of Health, Education, and Welfare, 1979), and after the procedure 4 weeks are needed for cell culture and analysis. By this time the fetus has begun to quicken, or move, which causes parents to begin to perceive it as a potential "future child" with all the corresponding fantasies and hopes (Blumberg, Golbus, and Hanson, 1975). Because the resulting therapeutic abortion takes place during the fourth month of pregnancy, it cannot be performed by aspiration as is the case during the first weeks of pregnancy. Couples who elect abortion following an unfavorable diagnosis experience physical and emotional effects that are not unlike those experienced by parents of a stillborn child (Silvestre and Fresco, 1980).

According to the study by Blumberg, et al. (1975), the decision to terminate a pregnancy because of a genetic defect is one of the more shocking and traumatic experiences that a married couple endure. The majority of couples studied by Adler and Kushnick (1982) reported that the termination of pregnancy was a tragic event. The termination was preceded by a 24- to 36-hour waiting period. They reported that for the women, this period of waiting to terminate the life of a moving fetus was agonizing. Blumberg et al.'s (1975) study of 13 families that had undergone amniocentesis and elective abortion revealed that 12 of 13 (92 percent) of the women and 9 of 11 (82 percent) of the men were seriously depressed.

Couples in Adler and Kushnick's (1982) study of 15 families revealed that most mothers experienced a brief period of denial followed by a combination of feelings: sadness over losing the baby; relief that it was over; guilt; bitterness as to why it happened to them and not to others; and doubts about their ability to reproduce satisfactorily. For the majority of mothers, this phase lasted 2 to 3 months, and in some cases persisted more than one year. Husbands in this study saw themselves as the family "realists." According to the authors, their decisions seemed to require less soul searching as compared with their wives.

Despite the emotional trauma of the procedure, most couples in both studies reported they would repeat the course of action, and consider a therapeutic abortion preferable to the alternative birth of a genetically defective child.

Because families who abort a genetically defective fetus are at risk for psychological sequelae, Blumberg et al. (1975) strongly recommend that physicians inform the couple of the experiences of others, and discuss the method of abortion in order to promote a well considered decision. Following the abortion, they strongly recommend that couples reveive supportive counseling or psychotherapy.

Improved technology may lessen the trauma of abortion following amniocentesis. A relatively new procedure, chorionic villi sampling (CVS) may be performed at 8-10 weeks gestation. It is a painless procedure that does not involve the insertion of a needle into the amniotic cavity. Instead, it samples the tissue outside of the developing embryo by means of a plastic catheter that is introduced into the vagina and through the cervical opening. The results of the genetic analyses, either chromosomal or biochemical, can be completed in 25 hours. If a genetic defect is detected, elective abortion is possible in the first trimester of pregnancy (Pergament, Ginsberg, Verlinsky, and Halprin, 1984).

Unfortunately, little research is available on parents who, following the diagnosis of a genetically defective fetus, elect to carry the fetus to term. It is reasonable to presume, however, that these parents will spend the rest of the pregnancy in shock and grieving, anticipating the birth of the defective child. For fathers, the developmental tasks noted by Duvall will take on new, ironic meanings. Not only must the father plan for the child's arrival, but now he must anticipate an impending tragedy requiring skills, resources, and services which he may be unaware of. The developmental task of supporting his wife will also take on a new meaning. Instead of joining his wife in hopeful anticipation, he may have to comfort his wife in their mutual sorrow. They may regret having had the amniocentesis. Said one expectant father after learning that he is yet-to-be born son had Down syndrome:

> I don't know why we even had the amniocentesis. They recommended it because my wife is 36 years old. But we're not the type to have an abortion. It really hasn't helped knowning -- my wife just cries all of the time.

While amniocentesis and CVS can help predict if a child will be born with a handicap, such knowledge will not be without costs to the parents. Parents who receive a positive diagnosis for a genetic defect will not only be forced to consider or reconsider moral questions regarding abortion and quality-of-life issues, but they will also face a profound loss as well. The feared tragedy is now confirmed, and the time of pregnancy, once filled with hope and anticipation, now becomes a time for resolving painfully difficult moral dilemmas.

STAGE THREE: THE CHILD BEARING YEARS

The birth of a child, especially a first child, signals many changes for the family: not only does a new dependent individual enter the family's social equation, but new roles and redefinitions of old roles are required of family members. As the first child is born, so are new family roles "born." Wives become mothers; husbands become fathers; parents become grandparents; only children become siblings.

Below are developmental tasks, adapted from Duvall (1962), that fathers will face during the childbearing years:

1. Reconciling conflicting conceptions of his role as a father. While many men grew up with a narrow definition of the role of the father, many are eager to actively participate in the daily routines of child rearing (Young and Hamilton, 1979). Consequently, many men will need to resolve the discrepancies between the fathering role they grew up with and the role they would like to assume.
2. Accepting his share of responsibilities for the child. As the father's role changes, so will the nature of his involvement with his child. One of the most noteworthy changes is fathers' participation in caregiving responsibilities. The level of a fathers' involvement in caregiving activities will be reflected in the strength of the child's attachment to the father, according to a study by Kotelchuck (1976). He observed that children who did not relate to their fathers (as indicated by children who spent less than 15 seconds with fathers upon their arrival) were primarily from families where the father was seldom the caregiver. Ross, Kagan, Zelazo, and Kotelchuck (1975) found a significant relationship between the child's attachment

behaviors and the number of diapers changed by the father in a week! Kotelchuck (1976) suggested that there seems to be a minimum level of paternal caregiving necessary for a relationship to exist. Lewis and Weinraub (1974) suggest that fathers need to be encouraged to assume more caregiving responsibilities to strengthen father-infant attachment.

3. Maintaining breadwinner status. Despite fathers' increasing interest in being more involved in the daily lives of their young children, and despite the increase in working mothers (45 percent of all mothers of preschool age children work, according to the U.S. Department of Labor, 1980 statistics), most fathers are still accorded the bread-winner's role in the family. Because employers rarely promote people who work less than full time, and because job sharing remains more of an ideal than a reality, many fathers face the same dilemma as single parents or so-called "super-moms." That is, how can a father provide for his family's economic well-being, remain involved and available to his children, and still have time and energy for his wife and himself?

4. Conforming to new regimens that incorporate the child's needs. First- time fathers will experience, first-hand, the effects of an infant whose needs will take priority over those of other family members. The infant's sleep and feeding schedules will require major adjustments in the father's life.

5. Encouraging the child's full development. The growing research on fathers and their young children strongly suggests that fathers affect their children's development in significant ways. A father's greatest contribution to his child's early development appears to be his role as the child's play partner. While researchers found that mothers were more likely to pick up their babies for caregiving purposes, fathers most often held their children to play with them (Lamb, 1976). Moreover, fathers' play is clearly different than mothers' play. Power and Parke (in press) found that fathers of 8-month-old infants engaged in significantly more physical games, such as bouncing or lifting, than mothers. Regarding the fathers' style, Brazelton states: "The father adds a different dimension (than the mother), a sort of play dimension, teaching the baby about some of the ups and downs - and also teaching the baby another important thing: how to

get back in control" (Collins, 1979, p. 50). Fathers' play may also have an important impact on the child's later social and cognitive development (Clarke-Stewart, 1980; Pedersen and Robson, 1969). In a summary of studies on paternal characteristics, Weinraub (1979) concluded that the characteristics of the father that are most clearly related to optimal child development, particularly in boys, include paternal warmth, acceptance, and involvement.

6. Redefining himself as a father. For many men, becoming a father will profoundly change their lives. Many men regard fatherhood as a rewarding time of personal redefinition. Parke (1981) noted: "Fathering often helps men clarify their values and set priorities. It may enhance their self-esteem if they manage its demands and responsibilities well" (p. 11).

Adjusting to the Father's Role

The husband's adjustment to fatherhood can be profound. If he is becoming a parent for the first time, he experiences a major developmental milestone in his own life that makes him take stock of his accomplishments, and his satisfaction with his career, family, and marriage. A new baby may stimulate him to re-examine his life goals.

Numerous researchers have found that both mothers and fathers often experience depression and mild stress after the birth of a new child. These feelings may result from fatigue, economic worries, changes in routine, and role adjustments. Becoming a father is a happy, but at times difficult experience.

Greenberg and Morris (1974) studied fathers' reactions to their newborn infants and used the term engrossment to describe the bond that develops between father and infant. More than mere involvement of a father and his infant, engrossment refers to that point in the father-infant relationship when the infant assumes an integral role in the father's life, and the father, in turn, feels an increased sense of self-esteem and worth. The authors note seven characteristics of engrossment:

1. Visual awareness of the newborn. The father perceives his newborn to be attractive or beautiful.
2. Tactile awareness of newborn. The father desires and derives pleasure from contact with his newborn child.
3. Awareness of distinct characteristics of the newborn. The father becomes aware of and can describe the unique characteristics of his child.
4. The father perceives the infant as perfect.
5. The father feels a strong attachment to the newborn. Consequently, he focuses much of his attention on the newborn.

6. The father is extremely elated.

7. The father feels an increased sense of self-worth. For many men, becoming a father for the first time provides opportunities for personal reflection and redefinition.

A father's joy and the child's appeal, as demonstrated by these characteristics of engrossment, will help a father compensate for many of the adjustments he will have to make in his life.

The Initial Crisis of the Child's Diagnosis

Given the anticipation the father experiences prior to the child's birth and the father's readiness to attach to his child, it is not difficult to understand the impact that a child who is diagnosed as handicapped will have on the father.

A crisis for a family has been defined as an event above and beyond normal difficulties for the family (Kirkpatrick, 1955). An event that is permanent and involuntary (such as a child's handicap) will create a greater crisis (Price-Bonham and Addison, 1978) than an event that is discrete or short-term. According to Wikler (1981), the impact of the child's diagnosis will be the most disturbing crisis parents will face during the handicapped child's life. However, as we shall see, it will not be the last crisis.

Wikler contends that parents of handicapped children will be subject to periodic, stressful crises throughout their children's lives. These crises fall into two categories: those crises that occur when there is a discrepancy between their expectations for the child's development and their child's actual progress; and those experienced only by families with handicapped children.

When parents receive their child's diagnosis, parents' dreams for their fantasized ideal child are often abruptly crushed. Parental grief is often exacerbated by professionals' insensitivity at the time of diagnosis. Price-Bonham and Addison (1978) note seven major errors professionals make relative to informing parents of a child's disability: delay in defining the problem; false encouragement of parents; too much advice on matters such as institution- alization; abruptness; being hurried; a lack of interest; and a hesitancy to communicate.

Roos (1978), a father of a mentally retarded child as well as a professional in the field of special education, bitterly recalls the insensitivity he and his wife experienced at the time of his son's diagnosis. He writes of the doctor's reluctance and delays in sharing the diagnosis, and the "parent as patient" attitude reflected by the physician who offered Roos and his wife tranquilizers when they expressed anxiety over their child's condition. Roos claims that many doctors regard mental retardation with "professional hopelessness" because they are impotent to cure it. This negative attitude and subsequent mistreatment of parents occurs at such a vulnerable time that it can exacerbate parents' grief and jeopardize their future relationships with doctors and other professionals.

None of the fathers of children with Down syndrome that Erickson (1974) met with knew anything about the disability at the time of their child's diagnosis. Some fathers reported difficulty obtaining information from the doctors, and others only learned about the disability after their wives had been informed. The fathers recommended that professionals wait to inform the parents of the diagnosis until both parents are together, and provide parents with a supportive and knowledgeable person to talk to during this time. As one father said: "There is no optimal time to be told your child has Down syndrome but there is an optimal way in which parents can be informed" (Erickson, 1974, p. 23).

Adaptation after the Initial Diagnosis. Following the diagnosis, the parents may grieve the loss of the hoped-for child. It is during this time that parents may, in their anger and frustration, seek to hold someone -- themselves, their spouse, their doctors, or God -- responsible for their child's handicap. When the evidence of the handicap is not clear, like it is with Down syndrome, but slow to emerge, parents may alternately accept and deny the existence of the handicap. The following three exerpts from Josh Greenfeld's A Child Called Noah (1979a) illustrate one family's denial, realization, and blame:

> Noah still strikes me as sluggish, apathetic, not very alert. But Foumi's convinced he's all right. I worry about him in a deep way (p. 39).

> Let's face it: Noah has temper tantrums, he does not walk by himself, he is unable to talk coherently. We live in a shadow of a doubt and worry about him constantly (p. 48).

> When I stay home all day and observe Noah constantly it becomes apparent to me that he is a disturbed child. I cannot get angry with him. I cannot get angry with myself. I cannot get angry with Foumi. But she can get angry at me and America. Wanting children in general was always a vanity of mine; she did not want children at all. She particularly did not want to have a child when she was pregnant with Noah. But being broke and in America, an abortion could not be seriously

> considered at the time. . . Also we wonder about the obstetrician now, did she induce Noah's birth too early? Did she deprive Noah of proper nourishment by insisting that the eighty-eight-pound Foumi diet? (p. 53)
>
> Shit! I wish we had not induced him. . . I thought by marrying outside of my race that bad genes -- the diabetes on my father's side, the mental illness of cousins on my mother's side -- could be eliminated. Instead, I have further scattered bad genes (p. 61).

Josh Greenfeld's concern about his son's delay and his wife's denial of the problem is an example of how husbands and wives may adapt in different styles and at different paces to their child's handicap. Differences in adaptation can place added stress on marriages (Price Bonham and Addison, 1978). Opportunities to effectively support one another may be diminished if, for instance, one parent is grieving and the other is worried about the burden of care presented by the child's special needs (Wikler, 1981).

The impact that the child's handicap will have on the father has been investigated by several authors and researchers. Cummings (1976) noted that because fathers are playing a larger role with their children, "there is increasing likelihood of fathers experiencing the handicaps more immediately and sentiently than did fathers only two generations ago" (p. 247).

His survey of fathers with mentally retarded children revealed that fathers were often depressed and preoccupied with their children's special needs, many felt inferior as fathers, and many were dissatisfied with their children and spouses.

Fathers have also been found to perceive their handicapped child as a threat to their self concept. Fathers who view their handicapped child as an extension of their egos are apt to become more isolated and to reduce or withdraw from social interactions (Call, 1958; Illingworth, 1967; Kohut, 1966).

The sex of the handicapped child appears to have an effect on the father. Tallman (1965), Farber (1972), and Farber, Jenne and Toigo (1960) found that the child's handicap had a greater initial impact on the father if the retarded child was a boy. Fathers may also be especially vulnerable to extrafamilial influences and social stigma caused by the child's handicap (Tallman, 1965).

The difficulties experienced by fathers may have second-order effects on other family members. Several authors have suggested that the father's attitude may set the pattern for the attitudes that other family members' in the home form about the handicap (Price-Bonham and Addison, 1978; Peck and

Stephens, 1960). Farber's (1972) finding that parents of a retarded boy show a lower degree of marital integration than parents of a retarded girl supports this notion (Peck and Stephens, 1960; Turnbull, Brotherson, Summers, and Turnbull, in press). The greater impact on the father by the retarded son will affect the couples' marital integration.

The father's reaction to diagnosis will influence the impact of the child on the marriage. Tavormina, Ball, Dunn, Luscomb, and Taylor (1977), in an unpublished manuscript as noted by Gallagher, Cross, and Scharfman (1981), suggest that there are four major parental styles in adapting to the crisis of having a handicapped child.

- The father divorces himself from the child, absorbing himself in work or outside activities, leaving the mother entirely responsible for the child.
- Both parents reject the child, who is often institutionalized as a result.
- The child becomes the center of the family's universe, and all family members subordinate their needs to accommodate the handicapped child.
- Both parents jointly support the child and each other while maintaining their individual identities and an approximation of normal family life.

Disproportionately high desertion rates by fathers of handicapped children have been reported (Reed and Reed, 1965) as well as high divorce rates in families with handicapped children (Tew, Lawrence, Payne, and Rawnsley, 1977). Some researchers (Schufeit and Wurster, 1976) claim that, when matched for social class, the divorce rate for families with mentally retarded children does not differ significantly from the rate for families with nonhandicapped children. Turnbull et al. (in press) attempt to resolve the mixed research results by suggesting that for many marriages, the impact of a child's handicap can be the "straw that breaks the camel's back."

Conversely, many families claim that a child's handicap has strengthened their marriage and brought the family closer together. Gath's (1977) study showed that while negative measures were higher for a family with children with Down syndrome, this group also had higher positive measures when compared to families with nonhandicapped children. Almost half of the families felt that their marriage was strengthened after the birth of the handicapped child.

It is important to note that each parent's reaction to the diagnosis will be unique and will depend, in addition to other factors, upon the supports available, the severity of the infant's handicaps, and the child's prognosis. These intervening variables will be discussed later in the chapter.

STAGE FOUR: FAMILIES WITH PRESCHOOL CHILDREN

A family with a preschooler will devote considerable time and energy to encouraging their child's development. Duvall (1962) outlines many of the developmental tasks required of a preschooler:

1. Settling into healthful daily routines of rest and activity.
2. Mastering good eating habits.
3. Developing physical skills appropriate to his stage of motor development.
4. Mastering the basics of toilet training.
5. Becoming a participating member of the family.
6. Beginning to master his impulses and to conform to others' expectations.
7. Developing healthy, emotional expressions for a wide variety of experiences.
8. Learning to communicate effectively with an increasing number of others.
9. Developing an ability to handle potentially dangerous situations.
10. Learning to be an autonomous person with initiative and a conscience of his own.

Although these significant developmental tasks always require some parental guidance and encouragement, the nonhandicapped child's acquisition of these skills is much more independent than that of the handicapped child. A developmental disability will often have significant effects on all of the child's developmental tasks. Consequently, some developmental tasks will not be accomplished during the child's preschool years, and others may never be accomplished. Normally trying periods, such as the so-called "terrible twos" may extend for several years. Developmental milestones that nonhandicapped children achieve with relative ease will require extraordinary encouragement from the handicapped child's parents and teachers.

The child's delayed development will have an impact on the parents during this stage of the family's life cycle. Because the period of intense nurturing which occurs during the child's infancy and preschool years must be sustained for a family with a developmentally disabled child, the need for one parent -- usually the mother -- to be home and available will also be extended (Wikler, 1981). For fathers, the usual roles of playmate or model for their children will be diminished or non-existent with children who are moderately to severely handicapped (Gallagher, Cross, and Scharfman, 1981).

It is during this stage that the child's disabilities will become more obvious. When the child does not attain normal developmental milestones, parents are at risk for increased stress. Two of Wikler's (1981) five predictable crises resulting from a discrepancy in expectations of the child's development occur during this stage -- when the child should have begun walking (12-15 months) and talking (24-30 months). These poignant reminders of their child's disability may reawaken the parents' grief for the loss of their fantasized normal child. Further, Wikler contends that as the disability becomes more apparent, parents will experience stressful stigmatized social interactions.

The Child's Impact on Parent Roles and Concerns. Because of the stigma, or physical evidence of the child's handicap, fathers and mothers may face "hostile stares, judgemental comments, murmurs of pity, and intrusive requests for personal information whenever they accompany their child to the store, on the bus, or at the park" (Wikler, 1981, p. 282). Fathers, more so than mothers, are affected by the physical child of a child's disability and are more sensitive to how the child may affect the family's social and community image (Price-Bonham and Addison, 1978). Fathers of handicapped preschoolers will need information on how to answer questions from relatives and strangers, encourage their child's development, and obtain additional information on the disability itself (Meyer, Vadasy, Fewell, and Schell, 1982).

Several authors have noted that fathers express more concern than mothers over future problems, such as economic and social dependency, and legal and educational matters (Hersh, 1970; Love, 1973; Meyer, et al., 1982). Liversidge and Grana (1973) report that at a meeting, fathers of deaf preschoolers wondered aloud "Will she be happy?" "Will he have normal children of his own?" and "Will he be able to earn a living?"

Fathers' orientation towards the child's future is a function of traditional parental roles that may be intensified when a handicapped child is present. Fathers, according to Gumz and Gubrium (1972), have a tendency to perceive their mentally retarded children in terms of an instrumental crisis, meaning they are especially concerned about the cost of providing for the child; whether the child will be successful; and whether the child will be able to support herself in the future. Mothers, conversely, have a tendency to experience the birth of a handicapped child as an expressive crisis. This means that mothers will be especially concerned with the emotional strain of caring for the retarded child; the desire that he get along well with others; and be happy regardless of academic achievement or job success.

While parental roles and concerns appear to be somewhat more defined in families with handicapped children, they are by no means exclusive. Gumz and Gubrium found that a high percentage of mothers were concerned about the high cost of raising a retarded child, and fathers of handicapped children were also concerned with the day-to-day concerns of raising a child with special needs. Fathers at the SEFAM (Supporting Extended Family Members) Fathers program at the University of Washington frequently discuss the emotional impact of the child's handicap on the family and other typically expressive concerns, such as feeding and toilet-training. Said one father when asked if he had changed as many diapers for his older, non-handicapped daughter as he now does for his handicapped daughter:

> No way. I think it's more the mom's role, but it shouldn't be. It's just the way society thinks. But when you have a handicapped child, it can change your whole outlook on life. It's like someone dropped a curtain in front of you -- you have to change. If you had a normal kid, things would have been trompin' along, and mom would have continued changing the diapers. But when you have a handicapped kid, you have to start thinking about new ways to do things -- that means changing diapers and stuff (Meyer, 1982).

Like mothers, fathers desire to do something that will ameliorate their child's disability. However, many fathers -- as well as mothers -- are uncertain of what their role should be. Gallagher et al. (1981) studied parents of young handicapped children and found that

> Across all groups there was general agreement that there should be more father involvement with the handicapped child. The fact that this does not happen or has not happened is an area in need of investigation, but there is no doubt that it should happen (p. 12).

Fathers Program Needs. Parent involvement components of early intervention programs have the potential to facilitate fathers' involvement with their handicapped children. However, many so-called parent programs are functionally "mother programs" because they are often held at times inconvenient for fathers, and tend to reflect mothers' concerns (Meyer, et al., 1982). Markowitz's (1983) exploratory study reported several factors determining fathers' participation in preschool programs. Interviewing directors of preschool programs for young handicapped children, Markowitz found that:

- almost 50 percent of the directors reported that fathers who had a traditional concept of parents' roles were less likely to become involved in their child's education.
- 40 percent mentioned that fathers are more likely to become involved if the child has a special meaning to the father (namesake, first born, first son).

- Two-thirds of the directors noted that the fathers' work schedule will influence fathers' level of involvement. They reported that fathers who do shiftwork, are unemployed, or have flexible schedules are often more involved.
- Over 50 percent of the directors also noted that fathers will be more likely to be involved if the child has a severe or specific handicap (such as Down syndrome or cerebral palsy) than if the child has a mild or unspecified developmental delay. This suggests to Markowitz that fathers may need or want more evidence of the child's disability than mothers to convince them that their participation is important.

Markowitz also concluded that fathers who do participate are in their mid 20s to early 30s in age, and are more educated than those who do not participate. However, Crowley, Keane, and Needham (1982) reported active involvement in a group of lower- to middle-class fathers of deaf children in the economically depressed South Bronx.

Programs especially designed for fathers, reflective of their often instrumental concerns, and held at times convenient to fathers may be helpful. SEFAM's Fathers Program has reported that fathers who had participated in the program reported significantly less stress, guilt, and depression than newly enrolled fathers. Fathers in the program also reported more satisfaction on several measures. Wives of men who had participated in the program also reported less stress, pessimism, and depression, as well as greater satisfaction than wives of newly enrolled fathers (Vadasy, Fewell, and Meyer, in preparation). This suggests that programs for fathers of handicapped preschoolers may be valuable for fathers and provide second-order benefits for mothers as well.

These benefits to both parents can be especially helpful for parents of handicapped children in the preschool stage of the family life cycle. It is during this stage that the child's disability can deeply change the parents' relationship. Mothers may expend prolonged periods of time attending to the child's needs, and fathers may "view the retarded child as interferring with his previously companionate relationship with his wife" (Farber and Ryckman, 1965, p. 1). Couples may go years without socializing outside of the home (Illingworth, 1967). Many may give up activities they previously enjoyed together, according to Schonnell and Watts (1956), who also found that more fathers (26 percent) than mothers (18 percent) report having to alter their social life.

STAGE FIVE: FAMILIES WITH SCHOOL-AGE CHILDREN

Families with nonhandicapped children use this stage to encourage the child's independence and growth. According to Duvall (1962), children in this stage will accomplish the following developmental tasks:

1. Learning the basic academic, emotional, and life skills required by school children.
2. Mastering the appropriate physical skills.
3. Developing meaningful understanding for the use of money.
4. Becoming an active, cooperative family member.
5. Increasing abilities to relate effectively to others, both peers and adults.
6. Continuing to learn to handle feelings and impulses.

As with the previous stage, a child's handicap will deeply affect the goals that are expected of and attained by a child at this stage.

Parents will be at-risk for stress at the very beginning of this stage. Wikler (1981) contends that the beginning of public school -- when the child enters a special education program instead of kindergarten or first grade -- is a stressful period for parents of handicapped children. They are reminded of the child's delay in a new way, and are further stigmatized. By being placed in a special education classroom, the child, and therefore the family, is publicly labeled as different.

Even parents who desire to have their children "mainstreamed" with other non-handicapped children may experience stress when they are reminded frequently of the discrepancy between their child and the nonhandicapped peers (Gallagher, Beckman, and Cross, 1983). According to a review by Turnbull and Blacher-Dixon (1980), other aspects of mainstreaming that may be stressful for parents are: sharing the handicapped child's stigma; feeling a lack of common interests with the other parents; worrying about their child's social adjustment; or providing support services necessary for the handicapped child in the nonhandicapped school setting.

As the discrepancy grows between the child's size and developmental capabilities, Wikler says, parents will experience increased stressful public encounters. Chronic problems, such as a lack of feeding or ambulatory skills, will be more burdensome as the child grows older and larger. Handicapped children often have stressful behavior, seizure, or health problems that are exacerbated as the child grows older.

> We thought we were, for the most part through with the toilet cleanup details that no matter how much we rationalize and intellectualize are utterly demoralizing. But last night Noah let loose again in his training pants -- his second accident of the day (Greenfeld, 1979b, p. 5).

Because of the difficulty parents often face obtaining qualified baby sitters, respite care opportunities for family members may be decreased as the child grows. Another problem parents of school-age handicapped children often face is obtaining adequate information about coping and managing daily living tasks for handicapped children of this age. When available, management programs and books often address the problems of younger children instead of the chronic problems parents of older children may face.

As mentioned earlier, a father's expectations and acceptance of the handicapped child often play a large role in determining the family's attitudes toward the child. Fathers' perceptions of the handicapped child may, however, be influenced by external sources, such as the child's school placement. Meyerowitz (1967) compared three groups of children: moderately retarded children in a special class; moderately retarded children in a regular class; and nonhandicapped children in a regular class. Meyerowitz reported that fathers favored the retarded children placed in the regular class. The fathers of the moderately retarded children in the special class had a poorer estimation of their children's abilities and lower occupational expectations than did fathers of moderately retarded children placed in the regular class.

Wikler (1981) has noted other characteristics of a developmentally disabled child that may also contribute to parents' negative perceptions. These include an increased visibility of the deviance; decreased I.Q. levels; increased age of a male disabled child (especially if over 9 years); and first born status.

Cummings (1976) studied 60 fathers of school-age children with mental retardation. Using four self-administered tests, Cummings sought to assess the fathers' prevailing mood (especially as it was influenced by the mentally retarded child); their self esteem (both generally and in terms of the fathers' evaluations of their worth as fathers); their interpersonal satisfactions with family members and others; and their attitudes towards childrearing.

When compared to an equal number of fathers of nonhandicapped children, Cummings found that fathers of mentally retarded children showed significant differences on three of the four variables. On the variable of prevailing mood, fathers of mentally retarded children were depressed and preoccupied with their childrens's special needs. The interpersonal satisfaction variables revealed significant decreases in the fathers' enjoyment of the index child, and their evaluation of their wife and other children. Self-esteem variables revealed that these fathers scored lower on expressed self-acceptance and a sense of paternal competence. According to Cummings, this suggests that these fathers may feel relatively inferior in their roles as fathers, and in their male roles.

When clustered by age, Cummings found that fathers of older handicapped children (9-13 years) showed slightly lower psychological stress levels than did fathers of younger (4-8 years) handicapped children. Older fathers also showed slightly lower ratings on depression, and higher on both enjoyment of child and evaluation of wife.

These data, however, are inconsistent with studies reviewed by Gallagher, Beckman, and Cross (1981), which suggest that the child's increasing age is related to increased stress, due to the increasing difficulty of managing the older handicapped child and the greater visibility of the handicap.

STAGE 6: FAMILIES WITH TEENAGERS

Teenage years are a period usually characterized by the adolescents' attempts to establish their own identity and differentiate themselves from their parents. Again, the experiences for families with handicapped children will be considerably different.

Duvall (1962) contends that nonhandicapped teenagers will need to confront the following developmental tasks:

1) Accepting one's changing body and learning to use it effectively.

2) Achieving a satisfying and socially accepted sex role.

3) Achieving more mature relations with agemates.

4) Achieving emotional independence from parents and other adults.

5) Preparing for an occupation and economic independence.

6) Preparing for marriage and family life.

7) Developing a workable philosophy of life that makes sense in today's world.

In every instance, the handicapped adolescent's experiences will be often disturbingly different than the experiences of a nonhandicapped teenager, causing special concern for the handicapped adolescent's parents. While the handicapped adolescent's body may change, the individual's cognitive handicap may limit his or her appreciation of the changes. Instead of achieving more mature relations with age-mates, the adolescent's developmental delay may become increasingly apparent as his body approximates an adult's while his abilities remain that of a much younger child, thus making it increasingly difficult for peers to accept the adolescent.

Although a handicapped adolescent may be preparing for a future occupation, the prospects for economic independence are usually dim. A mentally retarded son's lack of vocational opportunity can be difficult for fathers. Not only do fathers fear the long-term financial support that might be necessary

(Hersh, 1970), but because a mentally retarded son will not achieve his father's aspirations, the father may feel deprived of the satisfaction of the son's achievements. The handicapped adolescent's emerging sexuality may be especially troubling when he or she lacks the cognitive skills to be a capable, nurturing parent.

The onset of puberty, the beginning of menstruation in a girl, and parental concerns over the child's sexuality will cause stress for parents of handicapped adolescents (Wikler, 1981). This stress is stimulated by the discrepancy between the adolescent's physical appearance and mental and social abilities. Compounding this stress is parents' fears that their child will be sexually exploited.

While this stage poses troubling problems for handicapped teenagers and their families, the picture is not totally bleak. Parents of handicapped children who successfully weather these crises often experience great personal growth. Rud Turnbull, a father of a teenage, moderately retarded son and a lawyer specializing in disability law, demonstrates a father's potential for personal growth in this period:

> Jay forces me to deal with paradoxes: about how the exceptional in life (mental retardation) becomes unexceptional by reason of its familiarity, about how a person's disability (Jay's) contributes to another's ability (mine) by stimulating growth, and about how the mysteries of life (why me?) are answered, bit by bit, ever so certainly (Turnbull et al., in press, p. 3).

STAGE 7: FAMILIES AS LAUNCHING CENTERS

This stage typically begins when a family's first child leaves home as a young adult, and ends when the last child leaves home, leaving the parents with an "empty nest." Young adults, during this stage, may engage in the following developmental tasks: pursuing advanced education; beginning a career; learning to appraise and express feelings of love in an adult manner; and choosing a marriage partner (Duvall, 1962).

For families with a handicapped child, this "launching" stage may occur earlier or much later than usual. It may take place much earlier than usual for families who institutionalize their handicapped child, and may extend for the life of the child if the child lives with the parents as an adult.

Fathers of children with handicaps may anticipate this stage for years before it actually occurs. Vadasy, Fewell, Meyer, Schell, and Greenberg (1984) found that fathers of very young handicapped children are already concerned about the child's future well-being as an adult. While fathers of nonhandicapped children can look forward to a time when their children are independent and their expenses are reduced, fathers with handicapped children may be required to support the more dependent adult handicapped child emotionally and financially (Price-Bonham and Addison, 1978). This support throughout the child's adulthood will crystalize the relationship at a parent-child status (Birenbaum, 1971) rather than allowing the relationship to develop into a more mature form.

Wikler (1981) notes that at this stage, parents may face three significant crises: the child's 21st birthday; the question of placement of the handicapped child outside of the home; and the question of guardianship and care for the handicapped adult child.

The handicapped young adult's 21st birthday can be an especially troubling milestone for families. For the families Wikler studied, the handicapped child's 21st birthday was the second most stressful crisis for parents, following the initial diagnosis. The 21st birthday is a double crisis: while it normally symbolizes the child's independence, parents of a handicapped child will be reminded of the child's many needs before he or she can achieve independence. Further, the 21st birthday will signal a transitional crisis: schools will cease to provide services after this age, and adult services are often inadequate. Even when services such as group homes and sheltered workshops are available, parents will need to reassume many of the responsibilities that school staff had assumed to assure the child's well-being once he or she becomes ineligible for educational services.

De Boor's (1975) study of a father with a mildly retarded 21-year-old daughter finds him facing situations that other fathers may never face: bills from various agencies and doctors; his daughter's promiscuity, immaturity, and her inabilty to hold a job; and bureaucracies that are now seen as adversaries rather than allies. The father is no more certain of what will become of his daughter at age 21 than he was when she was seven. De Boor's study supports Wikler's (1981) contention that for many parents, the responsibilities for their handicapped child will increase instead of decrease with the child's age, as will the burden of care.

For parents who decide to place their child outside of the home, this stage may come unusually early. Deciding to place a child outside of the home is never an easy decision. Twenty-five years ago, parents were often urged to institutionalize their retarded children (Caldwell and Guze, 1960). More recently, in a spirit of de-institutionalization, more parents are encouraged to keep their retarded children at home. For many parents, especially those who have children with handicaps that demand almost constant supervision, the decision to institutionalize or not becomes a Hobson's choice. Keeping the child at home can become an unbearable burden for a family; yet they cannot face the prospect of placing the child in what is usually an inadequate institution. Two exerpts from Josh Greenfeld's A Place for Noah (1979b) illustrate this:

> ...I watch Noah guardedly. It is only a question of time before we will have to put him away. He is simply too retarded, too unable to take care of himself on an elementary level. The decision will somehow make itself... (p. 28).

> Today we saw the future, Noah's future. We went to Letchworth village, a fifty-year-old New York State institution in Rockland County...When I came home I looked at Noah. I had seen his fate - sooner or later he will have to go to one of these places. I thought about it and shuddered. My impression of Letchworth was worse than my memory of a visit to Dachau. I vowed I would have to send Noah to a better place, one where he would not be irrevocably and irretrievably lost (p. 28-9).

As Greenfeld discovers, adequate residential facilities are few and far between. However, even placing a child in an apparently adequate facility appears to have a psychic cost for parents. Hersh's (1970) study of families who placed their mildly mentally retarded children (age range 6-19 years) in a private facility with an excellent reputation revealed that:

> Certain parental responses...were so repetitive as to suggest a near universality of response in the group studied. The central themes were identified as loss, relief, guilt and ambivalence, and fulfillment and a sense of well-being (p. 99).

The sense of loss and relief, the author explains, often promoted guilt or ambivalence. If the parent was unable to prove that the institutionalized child was receiving services the family and community could not provide, the parental adjustment and placement were both in jeopardy. This study also noted that when parents lose the option of maintaining an active parental role, it can cause them great anxiety.

The inverse, deinstitutionalization, is not without its costs to parents. According to Gallagher, Beckman, and Cross (1983), deinstitutionalization is often associated with increased stress to parents. They cite research (Fotheringham, Skelton, and Hoddinot, 1972) that showed "declines in family functioning were associated with declines in the child's intellectual development for children who remained at home but not for children who were institutionalized" (p. 14).

STAGE 8: FAMILIES IN THE MIDDLE YEARS

The eighth stage in the life cycle, according to Duvall (1962), begins when the last child leaves home, and continues until the retirement of the principal breadwinner or the death of one of the spouses. Typically, this is one of the longest stages (Duvall estimates an average of 14 years). This stage may abruptly end at a spouse's premature death. Conversely, it may be delayed indefinitely by the presence of a dependent child who continues to live with the parents.

Parents of handicapped children often fall into the latter category, especially if their child is living at home with them. Parents of older handicapped children cannot anticipate enjoying many of the activities available to parents of nonhandicapped children of adult age (Birenbaum, 1971). Unless they have other children, they cannot look forward to the special joys of becoming grandparents. Parents of handicapped children will not be able to enjoy the freedom normally associated when children reach adulthood. Bob Helsel (Helsels, 1978), a father of a 30-year-old man with cerebral palsy and mental retardation, states:

> . . . (I)t seems to me as I approach retirement age and would like lots of personal freedom, (my son) will present a problem in limiting my ability to go where I want when I want. I don't know whether a solution will be found to give me the freedom that I would like to have or whether we'll just continue to be somewhat limited because of Robin. . . (p. 107).

As the handicapped child and his parents grow older, the handicapped child -- now an adult -- may be even more difficult to manage emotionally as well as physically. Bob Helsel conveys his inability to make his son happier.

> . . . I feel frustration in that I can't relieve his frustration, so my feelings about Robin and my attitudes toward him are certainly different than they were when he was young. Simply, as he has changed, I have changed; not in a way that makes me less accepting. As I just mentioned, I feel more frustrated with Robin now than I ever did before. . . . I wish I could help him recapture the kind of attitudes he displayed as a youngster. I wish I could relieve his frustration. I wish I could make him a happier

> person. But I don't know how to do this and I don't know whether anyone can do it. It just bugs me; it is a constant thing (pp. 105-106).

STAGE 9: AGING FAMILIES

The final stage of the family life cycle begins with retirement, continues through the death of one spouse, and ends with the death of the second spouse. The challenge of this age, Duvall (1962) contends, is maintaining ego integrity and avoiding the despair which may darken the final years. The goal for this stage of the cycle is successful aging through continued activity and comfortable disengagement.

The developmental tasks an aging father may confront are:

1. Finding life meaningful after retirement
2. Adjusting to the income of a retired worker
3. Making satisfactory living arrangements with his wife
4. Keeping well and maintaining physical health
5. Maintaining social contacts and responsibilities
6. Findings emotional satisfaction in intimate contacts with his loved ones
7. Facing the possibility of death in constructive ways.

During these years, a handicapped adult child may pose special problems for aging parents that their peers will not have to face. Now, with the prospect of death looming larger in their lives than ever before, parents will worry about their child's care after they die. Bob Helsel (1978), the father of a mentally retarded, cerebral palsied adult son notes:

> I suppose this is the biggest worry that a parent of a severely handicapped child has - what happens when I die? And there is no answer to that. As far as I know, there is no way to provide properly for him in the eventuality - at least I don't know of any . . . You can't amass enough capital to set up a private home for such a person. There just isn't an answer or a way to provide properly for such a child after your death (p. 106).

During this stage, parents not only usually expect to provide less and less care to their children, but aging parents often rely on their adult children to care for them when they become too old or too sick to care for themselves. Unless there are also nonhandicapped children in the family, parents will not be able to rely on their handicapped child for care or support.

However, the presence of a handicapped chld in the family can actually benefit some aging families by continuing to provide parents with meaningful roles. Bob Helsel's wife Elsie, offers this perspective:

> My husband and I will not have a footloose, carefree, romantic retirement lifestyle, but we will have something else - we will have the opportunity to feel needed as long as Robin needs us (Helsels, 1978, p. 100).

When older parents who have cared for their adult handicapped child at home are denied this sense of purpose, either through illness, a spouse's death, or infirmity, it can be especially hard on them. Josh Greenfeld noted in his journal:

> Last night I went to a meeting of the board at Noah's school. At the end of the meeting I was talking to the board president when an elderly man approached. "How's it going, Jim?" the president asked. Jim replied: "I miss him something awful." The president explained to me: "Jim's wife died during the winter. And Jim soon found he couldn't take care of his twenty-three-year-old son anymore and had to put him away!" "The house," Jim went on saying "feels awful empty" (Greenfeld, 1979a, p. 173).

A similar situation occurs in the cinema verite documentary Best Boy. The film chronicles the experiences of a mentally retarded adult (the director's cousin) and his aging parents. At the director's insistence, the parents enrolled the son in a day activity center for the first time and placed him in a group home, all in preparation for the parents' eventual deaths. Surprisingly, the son makes the transitions quite easily. They are far less difficult for him than they are for his parents, especially his mother who during the course of the film loses the two men in her life - her husband to death, and her son to a group home. In the end it is the mother, not the son, for whom the viewer feels the most compassion. At the end of the film, the viewer learns that the mother died a year after the film was made. Given the ease of the son's transition to a life apart from his parents, one questions, in retrospect, the timing of the son's placement. The film suggests that professionals, when recommending placement of a handicapped adult outside of the home, not only consider the child's dependence on the parents, but also the aging parents' dependence on the handicapped child as a reason for living.

IMPLICATIONS FOR SUPPORTING FATHERS OF CHILDREN WITH SPECIAL NEEDS.

Intervening Variables and Mediating Factors

The impact of a child's disability and the experiences the father has will depend on a complex interplay of intervening variables and mediating factors that often transcend the family life cycle. Child characteristics are examples of intervening variables that will account for a range of experiences and levels of stress felt by fathers.

As the lifecycle literature review suggests, the age of the child can be a variable in determining the amount of stress a father will experience. As the handicapped child grows, he may become more difficult to manage and his difference will become more apparent, increasing stressful situations for his parents (Farber, 1959; Price-Bonham and Addison, 1978;) In addition, parents of older children with mental retardation often feel more isolated, less supported, and more in need of services than parents of young children who are retarded (Suelzle and Keenan, 1981).

The sex of the child also influences many fathers. Grossman (1972) reported that fathers are more accepting of daughters who are mentally retarded than they are of sons who are mentally retarded. Similarly, a son who is mentally retarded appears to have a greater emotional impact on fathers than does a daughter who is mentally retarded (Farber, 1972).

Type and severity of handicap appears to account for differential paternal experiences. Cummings (1976) noted that fathers of mentally retarded children, when compared to fathers of chronically ill children, experience a greater negative impact. Parents of children with autism reported more overall stress, when compared to parents of children with Down syndrome and children who were served by an outpatient psychiatric clinic (Holroyd and McArthur, 1976). As children with autism grow older, they are more stressful and less likely to find adequate services and community acceptance (Bristol and Schopler, 1983).

The extreme stress felt by fathers of autistic children is evident in the writings of Frank Warren (1978) and Josh Greenfeld (1979a, 1979b). A father of a teen-age son with autism, Warren's frustration with inadequate social responses to his child's needs leads him to believe that social systems are subtly, but very effectively, killing his child. Greenfeld, who comes to refer to his older son Noah as being brain damaged rather than autistic, expresses similar frustrations in finding adequate educational, medical, and residential care for his demanding son. In order to dramatize the plight of children like his son, Greenfeld (1979b) made national television appearances advocating mercy killing of children like his son, contending "that if a society does not care it might as well kill, directly and swiftly and kindly, rather than indirectly and slowly and cruelly" (p. 159). While it is uncertain how many other fathers of children who are autistic or otherwise handicapped agree with Warren and Greenfeld that society is methodically killing their children, the two fathers speak strongly and clearly about the stress, frustration, and rage felt by many fathers of severely handicapped children towards society and a social service system ostensibly designed to help their children.

Mediating Factors

Throughout the family's life cycle, the severity of a family's reaction to reoccurring crises will be mediated by the family's interpretation of the stressful events, and their resources to manage those crises.

In order to successfully cope with stressful events, fathers may reinterpret or reframe the event. Turnbull et al. (in press) explains:

> Reframing involves both the ability to identify conditions that can be successfully altered and to initiate problem solving; and the ability to identify conditions beyond one's control and make attitude adjustments to live with them constructively. It is based on a positive perspective rather than a negative one (p. 7).

As the name implies, reframing requires adjustments in a father's personal philosophy.

> It's ironical: If Noah has proven debilitating to our dreams, he has also provided the material for a kind of realization of ourselves. It's not the realization either of us anticipated or wanted, but then one cannot predetermine the scenario one is destined - or doomed - to act out, either (Greenfeld, 1979b, p. 286).

Other fathers speak of new values and personal growth as a result of successfully coping with stresses associated with handicapped children. Said one father: "Before Eric came along I was on what you might call the corporate fast track. That's not so important to me any more. My family is more important to me now."

Given that fathers may set the pattern for a child's acceptance or rejection in the home (Peck and Stephens, 1960), a father's ability or inability to reframe stressful events can influence the family's emotional climate and the role the child will play in the family.

Still other fathers reframe their situation by providing support to other parents of handicapped children, often parents of newly diagnosed children. This reframing not only provides needed support, it also fosters a father's own personal growth. Being available to fathers and sharing experiences and information allows a father to transform a negative experience into a positive contribution.

Parental characteristics and access to resources can help fathers manage stressful events relating to their child's handicap. Farber (1960), Grossman (1972), Moore, Hamerlynck, Barsh, Spieker, and Jones (1982), and Rosenberg (1977) have found that class, education, and income are inversely related to stress in parents of special children.

Interpersonal supportive resources have been explored by Gallagher, Cross, and Scharfman (1981). Their data suggest that a major source of strength was the quality of the husband-wife relationship. Fathers of moderately to severely handicapped preschoolers reported that support from their wives and friends is very important, while support from neighbors is less important. In the chapter by Vadasy and Fewell, the authors note that mothers of severely handicapped children also rank spousal support as most important, both when the child was young and when the child attains adolescence.

Implications for Intervention

There is a growing realization among parents and professionals in special education that more is needed to be done to address the concerns of fathers of handicapped children. Cummings (1976) observed that fathers have "fewer opportunities to do something directly helpful for their handicapped child, something which provides concrete evidence of their loving, caring, and benevolent concern" (p. 253). Because organizations for parents and handicapped children offer fewer services for fathers, and request and obtain less participation from them, fathers have fewer opportunities to share their concerns and reduce their stress than mothers do, Cummings adds.

One approach to correcting this neglect of fathers is to try to increase their involvement in existing programs developed with mothers' needs in mind. However, encouraging increased father attendance at meetings primarily attended by mothers may not be beneficial for either parent. When Markowitz (1983) asked representatives of early childhood special education programs how mothers behave around fathers when they both participate in programs, almost half described mothers as quieter, "taking a back seat," intimidated, or self-conscious compared to their behaviors when fathers do not participate. Only 13 percent of interviewees reported a positive reaction, such as increased maternal comfort, to the fathers' presence. According to almost half of the program representatives, fathers who do attend activities or meetings are quieter and do not share feelings, information, or experiences as readily as mothers. It appears that in the interest of providing an opportunity for parents to openly express their feelings and obtain information reflective of their often different concerns, fathers and mothers may be served better in separate programs.

A few programs specifically designed for fathers of handicapped children now exist and, according to preliminary reports, appear to benefit the participants and their families.

Crowley, Keane, and Needham (1982) reported on a program for fathers of profoundly deaf children in the South Bronx. The overall goal of the program was to improve the quality of each father's involvement in his deaf child's school and home life. Secondary goals included helping fathers learn more about deafness and cope with their feelings and attitudes. These goals were achieved through topical discussions, and informal discussions of attitudes and feelings.

While no data were presented, the authors reported that fathers found the information presented to be helpful in understanding and dealing with their deaf children. They found that fathers after one year of involvement in the program were more objective in observing their children's behavior; were more willing to participate fully in all aspects of their children's development; solicited advice from group leaders and other fathers for ways of dealing with behavior problems; and were less apt to compare their deaf children negatively to siblings or hearing peers than the year before.

A program for fathers and their handicapped preschoolers that is examining the benefits of participation upon parents is Supporting Extended Family Members (SEFAM) at the University of

Washington. SEFAM, a Handicapped Childrens Early Education Program (funded by the Department of Education) is an outgrowth of a pilot Father, Infant, and Toddler Program, which has been offered at the University's Experimental Education Unit since 1978 (Delaney, Meyer, and Ward, 1980). Based on the pilot effort and a review of the research, SEFAM staff developed program activities that encourage a father to:

- learn to read his child's cues and interpret his child's behavior;
- develop an awareness of activities, materials, and experiences suitable to the child's current stage of development;
- practice his skill as the child's primary caregiver;
- learn more about the nature of the child's handicap;
- discuss his concerns with other fathers in a similar situation;
- develop an awareness that he, as a parent, will be his child's primary educator and advocate;
- explore the changing role of the father in today's society; and
- examine the impact of the child's handicap on the entire family structure (Meyer, et al., 1982).

SEFAM activities are built around three major components: support (father to father), involvement (father and child), and education (the father learning more about the implications of his child's disability). At bi-monthly meetings co-facilitated by a father of a handicapped child and a special education teacher, fathers share concerns, joys, and information during a "fathers' forum"; learn and enjoy activities with their children; and obtain information from guest speakers that reflect the participants' concerns.

Delaney (1979) studied the pilot Fathers and Infants Program (later called simply the Fathers Program as the children grew older). His research revealed that during free play sessions participants showed a significant decline in ignoring behaviors (both in terms of frequency and duration) across seven sessions. He concluded that by increasing the father's awareness of his child's development it was possible to significantly reduce the amount of the father's ignoring behavior.

Vadasy, Fewell, and Meyer (in preparation) compared fathers who were newly enrolled in SEFAM's Fathers Program to fathers who had particiated in the program for at least one year in order to determine whether a father's social supports, stress or self-esteem might change over the course of a fathers involvement. In addition to this treatment - no treatment comparison, they also retested eleven participants one year later to obtain a pretest - posttest measure. It was further hypothesized that fathers' participation in the program might have second-order effects upon their wives, who would experience increased support in their role. Both mothers and fathers were therefore asked to participate in the evaluation.

When controlled for child's age and parent's education and occupation, parents who had participated in the program, when compared to newly enrolled fathers and mothers, reported several benefits.

General stress - Fathers who had participated in the program reported significantly less stress than did newly enrolled fathers ($p = 0.04$). Fathers also reported they experienced significantly less stress due to their child's limited capabilities than did newly enrolled fathers ($p = 0.02$). The wives of the men who had been enrolled in the program experienced less stress ($p = 0.04$) resulting from their child's personality characteristics, such as acting out, than wives of new enrollees. After fathers had been enrolled in the program for one year, their wives reported less stress ($p = 0.05$) in dealing with problems than wives of new enrollees.

Self-esteem - Participation in the program appeared to have a positive effect upon both mothers' and fathers' perceptions about themselves. Fathers who had participated in the program rated themselves as successful significantly more often ($p = 0.04$) then did newly enrolled fathers, and perceived their families as having significantly fewer problems ($p = 0.03$) than newly enrolled fathers.

Social supports - Particaption in the program appeared to have a positive effect upon fathers' satisfaction with other extrafamiliar supports. Fathers in the program reported significantly more satisfaction ($p = 0.03$) with organized religion, and a similar trend was evident in their wives ($p = 0.11$). Veteran fathers were significantly more satisfied ($p = 0.03$) with the type of persons with whom they shared their problems.

Supportive trends. Although not significant, veteran fathers were also more satisfied ($p = 0.10$) with the amount of sharing they do with others. Wives of veteran fathers reported greater satisfaction ($p = 0.06$) with medically related professionals, as well as greater satisfaction ($p = 0.17$) sharing their happy moments with others than wives of newly enrolled fathers.

Fathers who had been in the program also reported less disappointment with themselves ($p = 0.09$), less guilt ($p = 0.03$), more healthy appetites ($p = 0.07$), less fatigue ($p = 0.06$), and less depression over the future ($p = 0.06$) than newly enrolled fathers. The wives of the veteran fathers reported less pessimism ($p = 0.10$) and less depression ($p = 0.11$) than wives of newly enrolled fathers.

While Vadasy et al.'s (in preparation) findings should still be regarded as preliminary, they support parents' and professionals' opinion that more needs to be done to address fathers' concerns.

Markowitz's (1983) interviews with early childhood special education program representatives revealed that, when asked how a father's involvement affects family functioning, two-thirds observed one or several of the following positive trends: improved family communication; reduced stress and tension; more sharing of burdens and responsibilities; enhanced family support system; increased acceptance of the child; more consistent discipline; and more harmonious family functioning.

Markowitz (1983), Meyer et al. (1982), and Turnbull et al. (in press) have made recommendations for programs which involve fathers. The following points, made by these authors are worthy of review.

Staff attitude towards fathers. Special education, like psychology, has for too long ignored the "other parent." Of the attention that psychologists have given to father, Parke (1981) has written: "We didn't just forget fathers by accident; we ignored them because of our assumption that they were less important than mothers in influencing the developing child" (p. 4). Programs will not be successful in increasing father participation unless staff believe that fathers are important, expect them to be involved, and treat them as equal parents (Markowitz, 1983). This will mean addressing correspondence to both parents, not just mothers; adapting program advertisements, brochures, and newletters to appeal to fathers as well as mothers; and providing male staff members in order to facilitate fathers' comfort (Markowitz, 1983).

Flexible scheduling. Evidence of a program's attitude towards fathers will be reflected in its staff's willingness to maintain a flexible schedule in order to accommodate fathers. E. Mavis Hetherington made a telling remark about psychology that is applicable to special education: "A major reason fathers were ignored (by psychologists) was that fathers were inaccessible. To observe fathers you have to work at night and on weekends, and not many researchers like to do that" (Collins, 1979, p. 49). As Hetherington suggests, a father's work schedule may interfere with his involvement in a program, and increasing father involvement may require flexible program scheduling. Two programs that have reported success in attracting fathers have either met on Saturdays (Meyer et al., 1982) or during evenings (Crowley et al., 1982).

Programs for fathers. As previously mentioned, fathers wish to be involved with their special child yet are often unsure how to show their love and concern for their child (Cummings, 1976; Gallagher et al., 1981). Fathers also have fewer opportunities than mothers to share their experiences and special problems related to the special child (Cummings, 1976). However, as Markowitz' (1983) data suggest, increasing fathers' attendance at so-called parents meetings (which are, in effect, mothers' meetings) may not benefit either fathers or mothers.

This suggests a need for programs that are designed for and reflect the interests of fathers. These programs should complement programs for mothers and the child's educational program. Due to the novelty of this concept, the ideal model for involving fathers has yet to be determined. SEFAM's Fathers Program shows promise, especially in urban communities. It has yet to be adapted for rural areas or for low income or minority populations.

Regardless of the model developed, programs that wish to address fathers' needs will help fathers if they provide fathers with the opportunity for:

Support. By providing fathers an opportunity to discuss their concerns with other fathers in a similar situation, programs can help decrease their sense of isolation and increase the social supports available to them. Through discussion, fathers can examine the impact the handicapped child has had on himself, his wife, and his entire family. Fathers who share their family's experiences with other fathers can increase each other's understanding of relatives' needs and how to help their family members cope with their individualized stresses. Fathers of handicapped children, like many fathers, are exploring the new roles and options available to men. Because most men lack models for the role of male caregiver, fathers interested in being nurturing parents need a supportive environment in which to gather information, ask questions, and share their thoughts about child development, discipline, eating habits, and other typical child-related concerns. In this respect a fathers' program is a men's group--supporting its members in roles that differ from traditional sex roles--as well as being a parent's group. In order to provide fathers with a positive model, as well as to insure fathers' comfort, these programs should be led by a male staff member, a "model" father, or preferably be co-facilitated by both.

Involvement. Programs that actively involve the father with the handicapped child can expand a father's knowledge of suitable activities and experiences that will be enjoyable for both father and child. Involvement in activities at the program can foster increased father-child involvement outside of the program. Given the father's importance as a child's play partner (Clarke-Stewart, 1980), increased father-child involvement may contribute to the child's cognitive and social development, as well as fostering attachment.

Programs for fathers and children provide fathers with an opportunity to practice caregiving skills. As research suggests, (Kotelchuck, 1976; Ross, Kagan, Zelazo and Kotelchuck, 1975), increasing caregiving has implications for increasing father-child attachment, as well as increasing the respite care that is available to mothers. When programs involve fathers and children, mothers have respite during the hours that the father and child are in the program and, as the fathers become increasingly comfortable at providing care for the special child, mothers' chances for additional respite are greater.

Education - Studies by Hersch (1970), and Love (1973) have shown that fathers - more so than mothers - are concerned with their handicapped children's future problems, such as educational, vocational, legal, and economic matters. Programs for fathers can provide information that will address these and other paternal concerns. Information may be written, presented by staff or guest speakers, or shared by father participants.

An educational component complements staff efforts to provide fathers with support and involvement. Studies comparing the relative superiority of parents groups that are primarily supportive with those that are primarily educational are inconclusive. However, it is believed that a program that combines educational and supportive approaches has the most to offer parents of handicapped children (Selignan and Meyerson, 1982; Tavormina, Hampson, and Luscomb, 1976).

Services for Fathers Across the Family's Life Cycle

The research that has been reviewed makes clear that fathers of children with handicaps have needs that change over the families' lifecycle. While programs for new fathers of young handicapped children can provide much needed services to traditionally underserved family members, programs that address fathers' needs and concerns are needed throughout the family lifecycle. Parents of older children with mental retardation report feeling less supported, more isolated, and more in need of expanded services than fathers and mothers of young mentally retarded children (Suelze and Keenan, 1981).

Knowledge of predictable crises across the family lifecycle allows interventionists to be proactive rather than reactive in alleviating family stress due to these crises (Wikler, 1981). Knowledge of fathers' needs allows interventionists to develop programs that reflect fathers' unique concerns. By expanding on these two bases of knowledge, programs can be developed for fathers that parallel programs for mothers and that are available across the child's lifespan. By providing programs for fathers over the child's lifespan, interventionists can not only insure that fathers have access to support and information; they can also make it possible for fathers, in turn, to better support their wives' efforts. As fathers become more informed and supported, more available to their wives and their handicapped child, the entire family's functioning is enhanced, enabling them to adapt to changing needs they will experience across the family's lifespan.

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Supports from Religious Organizations and Personal Beliefs

Rebecca R. Fewell

Families of Handicapped Children: Needs and Supports Across the Lifespan

Prepublication Draft

Supports from Religious Organizations and Personal Beliefs

Rebecca R. Fewell

When a person is born with an impairment, incurs a debilitating accident or illness, or, in the course of development, fails to develop to a level where he or she can fully participate in society, many difficult questions and challenges arise. The person and his or her family must try to answer the question why this has happened, and the family must find a way to meet the increased needs of the impaired member. In some cases, family members will assume responsibilities that will last for the remainder of their lives. Family members who take on these roles are seldom prepared to do so. They, as well as the impaired person, will need various kinds of support, depending on the handicapped family member's needs, their own needs, the resources available, and many other factors. Support for immediate family members will often come from extended family members, such as maternal and paternal grandparents, other children, friends, and neighbors. Support may come from institutions such as the schools, churches, medical centers, national or community organizations such as the Lions Club or Easter Seal Society, and government agencies that provide special services for the handicapped. Some persons will derive important support from their inner resources, personal belief systems, and religious affiliation. Theorists and researchers have provided a rationale for examining how beliefs, particularly religious beliefs, are used by parents of handicapped children to help them cope with the added stresses they experience. Findings from several studies will be reviewed, and the two types of support families are found to derive from their religion will be discussed.

Support from Religious Beliefs

Theorists in family interactions, Folkman, Schaefer, and Lazarus (1979) proposed a model of how individuals cope with stressful situations. The theorists feel an individual's successful appraisal of a situation is based on the availability of five coping resources: utilitarian resources, health/energy/morale, social support, problem-solving abilities, and general and specific beliefs. The category of general and specific beliefs includes religious beliefs which help individuals face unexplicable questions.

In a study of mothers of retarded children, Friedrich, Cohen, and Wilturner (in press) examined locus of control and religiosity, two variables they considered to be included in Folkman et al.'s category of general and specific beliefs. The investigators used the term "religiosity" to describe the role religious beliefs play in one's adaptation to life experiences. The researchers found strong evidence that religiosity serves as a "buffer" to many of the stresses associated with raising a handicapped child, particularly for younger, less educated mothers. According to these researchers, a variety of beliefs are associated with religiosity. Two of these beliefs are that a supreme being has a reason for selecting the parents to raise a child with special needs, and that this being is aiding their coping. The researchers identified locus of control to be an important moderator variable, as mothers who had more internal locus of control felt more positive about themselves and had a wider range of coping resources available to them than mothers with less locus of control. Of particular interest to the researchers was the finding that religiosity and locus of control were not correlated (r=.01), yet both operate as buffers of stress. Parents and families, they concluded, use different resources and styles for coping with stressful events, and these may vary from one time in the life cycle to another time.

Further information about the nature of religion and the role of beliefs in the lives of parents of retarded children comes from a study recently completed by the author. In an effort to investigate the types and amount of support available to parents of handicapped children, the author and her colleagues developed the Questionnaire on Family Support

Systems (Fewell, Belmonte, and Ahlersmeyer, 1983). The 14-page questionnaire was composed on six subscales, including one on religious organizations and beliefs. An analysis of the responses of 80 mothers to the questions on this subscale is presented in this section.

The subjects were solicited from mothers of children with Down syndrome who had written to the Model Preschool Center at the Experimental Education Unit, University of Washington for information and resources on the education of young children with Down syndrome. The mothers had written in response to an article that appeared in Family Circle magazine (October 1982). Questionnaires were mailed to 135 mothers living in all areas of the United States, and responses were received from 80 mothers. This represented a return rate of 60%, a rate that exceeded the estimate of reasonable rates (10-50%) anticipated from mail surveys (Sellitz, Wrightsman, and Cooks, 1981). The mean age of the mothers was 31.5 years. The mean age of the children with Down syndrome was 2 1/2 years.

The original Religion Scale (see Table 1) included 13 statements. Two subscales were subsequently formed. Six statements (1-6) were determined to be related to the church as a supportive organized body of persons, and six statements (7-12) were related to aspects of one's personal or spiritual beliefs. One additional question in the original scale was judged to be ambiguous for purposes of subscale classification;

it was deleted when responses on the two subscales were considered. In the questionnaire, these 12 statements were ordered randomly, and there was no indication as to which aspects of religion the questions tapped. Mothers were asked to assign a number from 0 to 5 to each statement, indicating their agreement or disagreement based on their own experience.

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Insert Table 1 about here

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The scores were as follows: 0-not applicable; 1-strongly disagree; 2-moderately disagree; 3-neither agree or disagree; 4-moderately agree; or 5-strongly agree. Table 1 includes the percentage of responses that were classified as not applicable, agree (strongly and moderately), neither agree nor disagree, or disagree (strongly and moderately).

When we compared mothers' responses to the first six questions on support mothers perceived from their church organization to their responses on the six questions on support from their spiritual beliefs, we found that mothers felt very different about the support they received from these two sources. Means, standard deviations, t values, and probabilities are seen in Table 2. Mothers reported significantly greater support from their personal or spiritual beliefs than from their religious organizations.

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Insert Table 2 about here

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Comparisons of mothers' responses within and across the two sets of statements offer important information on the difference in support from religious organizations and personal beliefs.

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Insert Table 3 about here

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First, as seen in Table 3, the mean percentage of responses which indicate agreement or disagreement with the statements on organized religion as a support reveal only small differences. As many mothers agree as disagree, and only a few less mothers indicate a religious organization is not applicable as a source of support in their lives.

The mean percentages of mothers' responses to the statements related to spiritual beliefs as supports reveal a very different pattern, with the mean percentage of agreements being over seven times the mean percentage of responses reflecting disagreement with the positive statements, and six times the mean percentage of responses indicating statements were not applicable to them. These differences indicate that significantly more mothers find their spiritual or personal beliefs to be sources of support and applicable to their daily lives than mothers who do not perceive support from their own spiritual beliefs.

Comparisons across the two sets of statements provide further insight into sources of support. The mean percentages of mothers responding that support from their organized church was not applicable to them (24%) was twice the percentage of mothers who indicated that support from their belief systems was not applicable (11%). Thus, 89% of mothers were able to relate to the questions about personal beliefs and could indicate their feelings about these statements, whereas 24% of the mothers did not feel statements regarding support from religious organizations were relevant to them.

Comparisons of agreements between the two sets of items also yielded differences. Of the mothers responding, 66% responded positively about support emanating from their beliefs, whereas only 29% of the mothers responded positively about support they experienced from their organized religious group. These findings indicate the support these mothers derive from their belief system was extremely important to them as they understand and cope with the experience of having a child with Down syndrome.

Comparisons of disagreements also yielded very different results. While 31% of the mothers disagreed with the positive statements of support from the church organizations, only 9% disagreed with the positive statements of support from their beliefs.

Finally, when we examined the percentage of mothers who neither agreed nor disagreed with these positive statements of support, slightly more mothers were indecisive about organized religious support compared to mothers who were indecisive about the support they derived from personal beliefs.

The results of this study suggest a theme that will be further discussed in this chapter. It appears that a parent's formal religious affiliation and the parent's spiritual or personal beliefs are separate systems of support that can be considered independent of one another. The results indicate mothers of children with Down syndrome experience significant religious support in their parenting role, particularly from their personal or spiritual beliefs. These are beliefs that are closely aligned with faith, with belief in a spiritual being, and with the efficacy of prayer. For some mothers, religious organizations have been a source of strength, but fewer mothers indicated they derived support from this source. The findings of this study on the importance of personal beliefs in a spiritual being support the finding of Friedrich et al. (in press), and of Vadasy and Fewell (see Chapter __) that religious beliefs are a source of support for parents of children with handicaps. Belief in a spiritual being appears to buffer stress and enables mothers to cope on a daily basis. The distinct nature of these two types of religious support makes it important to examine each in more detail in an effort to understand how they benefit parents.

Support From Religious Organizations

Religious organizations offer many different benefits to their members, and individual members may take away quite different types of support from any one of these organizations. Membership in a religious organization may offer parents of handicapped children several different kinds of support, including: a) instrumental support, b) emotional or social support, c) educational support, and d) structural support.

Instrumental Support

In describing support individuals derive from social networks, Unger and Powell (1980) use the term instrumental support to refer to material goods and services provided to alleviate financial and economic crises. A major mission of many religious organizations is to provide instrumental support for their members and others in need. Members of religious organizations often believe that the provision of this instrumental support is more important for the giver than it is for the receiver. By providing food, medical supplies, money, and other forms of goods and services to those in need, both within and outside of their group, members of church organizations are able to put into action their beliefs.

Emotional or Social Support

Within many religious organizations, there exist strong bonds of support between members. These bonds develop through members' frequent associations, and their common embrace of church doctrines and causes. Members of some organizations view their fellow parishioners as members of an extended family or a caring community (Ball, 1983). Members support one another in their joys and sorrows. For example, a red rose may be included at a church service to signify the church community's celebration of the birth of a child for the child's family. Members who may not know a new family may nevertheless participate in vows to help the family nurture their child in the common faith of the organization. The social support that church members can provide for peers is captured so well by Rabbi Harold Kusher (1981) who relates a story told by Harry Golden.

> When he was young, he once asked his father, "If you don't believe in God, why do you go to synagogue so regularly?" His father answered, "Jews go to synagogue for all sorts of reasons. My friend Garfinkle, who is Orthodox, goes to talk to God. I go to talk to Garfinkle." (p.122)

Within other religious bodies, supportive relationships may be experienced quite differently. When queried about support provided by members of her urban parish, a mother of a child with a serious impairment said:

> I have never felt any support from the members. I really doubt that they know who we are. We worship in the same church, but we don't know each other.

This statement is from a mother who attends church regularly and who reports her religion to be an important source of support in her life. She experiences this support although she does not seem to obtain support of a social nature from her church. The notion of religious support and what that really means is clearly a complex issue.

Whether or not a family finds support from a religious organization appears to be greatly influenced by many variables. Certainly, the history of the particular congregation is one determinant of its present behavior. The doctrines of the religious organization may be another factor, some groups fostering a more active ministry among members than others. The members themselves also bring their personal histories, strengths, and needs to the organization. These attributes shape what happens to the group as a whole, and affect the lives of individual members. Church members are, in turn, influenced by each other and by their transactions. The church leader or pastor may set the example for the rest of the congregation. Ball (1983) describes five roles that a pastor should be prepared to play to foster effective church-community linkages. It is clear that not all church leaders are able to be as informed a resource or as effective an activist as Ball describes. Some families will encounter church leaders who assume an advocacy role, although other families may not derive this benefit from their church or may not even desire it if supports from other sources are adequate.

Other factors that could contribute to the emotional or social support a family might experience from a local religious group are the size and location of the group. In very large groups which meet infrequently, persons may have few opportunities to get to know each other. In small groups where members may have to contribute more to the ongoing functions, (i.e., teach in the church schools, usher at services, work as missionaries, visit the sick) there may be more opportunities to know and support one another. In some areas of the country, religious organizations appear to be more central to the life of the community than in other regions. For example, in the South, a very high percentage of families are members of religious organizations and participate actively in the functions of their institutions. Likewise, in rural areas churches serve as gathering places for persons in the area, thus supporting the social life of the community. In some of these organizations, large extended family networks may characterize the makeup of the church membership, thus reinforcing both church and family groups. Many religious organizations have established procedures for responding to crises in the lives of their members. Church leaders and often individual members visit one another to express their concern and sadness. Fellow members attend important services to participate in rituals of particular value to another member. One such crisis may be the birth of a child with a handicap into the church community, and members and clergy in some religious groups may offer valuable support to the new parents and family.

While members of a religious organization may provide the family with support at the time of a crisis, such as the birth of a child with severe impairments, the long-term support churches provide such families may be far from ideal. Turnbull (1983) describes her family's experiences:

> Rud and I have not yet found a church that had a systematic plan for including handicapped children in the church school program ... I longed to have the church school director approach Jay and invite him into a program or

> explain options to me on how he could be included. This, however, has never happened (p. 14-15).

Educational Support

Religious organizations provide training for their members, regardless of age. This does not obviate the need for families within the organization to assume this responsibility; it simply supports their efforts. While the organization expects parents to provide religious training on a daily basis, the organization provides the more formal instruction, usually through a church school or through classes or training.

At times, religious education may provide very specific support in an attempt to provide children with a framework for understanding life's tragedies. Rabbi Kushner (1981) was asked to explain to neighborhood children and nursery school playmates why one of their friends had been killed in an accident. He provides a detailed account of the explanation he offered to these children. Additionally he reminds readers of the care with which such explanation must be given to children. "Children are particularly susceptible to feelings of guilt .... A wrong word, even by someone trying to be helpful, will serve to reinforce the feeling that it was, in fact, our fault." (p.101)

Parents of children with handicaps seek two kinds of educational support from their religious bodies. First, they want their handicapped child to have appropriate opportunities to participate in the organization's services. Turnbull's previous quotes and remarks illustrate that desire, as do these further remarks from her:

> Whereas we could always make the assumption that there would be a program for Kate and Amy, we could not make the same assumption for Jay. It has not been that our churches have tried to exclude Jay; however, they have not responded with appropriate alternatives for him (p. 14).

A second educational need families have is for guidance in how they might carry out some of their own responsibilities to their handicapped child. For example, they may seek help in how to explain to their child why he will not be able to participate in events his siblings experience. Or, parents may need help in explaining abstract religious concepts such as "God," the "Virgin Mary," or the "Holy Ghost" to a mentally retarded child.

Structural Support

Religious organizations, like schools and other institutions, provide a framework for helping persons adapt to new roles and responsibilities as they mature. This framework parallels the different milestones, stages, or events in the lives of church members. Another form of structural support is that offered through the rituals and practices of the corporate community.

The Developmental Milestones in Church Life. Although religious organizations define these steps differently, these events share common meanings and have functional roles in the lives of religious communicants. Each of these steps has a special meaning for a child and for the family as they grow, both in their relationship as family members, and as members of the larger church family.

Baptism. Shortly after life begins, parents who want their newborn child to follow the religious traditions of their family will seek the blessings of the religious body for their child. This ceremony of initiation involves the clergyman, members of the extended family, and often members of the religious body. It is a time for parents and other family members to make a commitment to provide religious training for the child, and for the child to be welcomed into the care of the organization.

Membership. After a period of religious education, when parents, the child, and the religious organization's representatives feel the child is ready to make a personal decision to follow the creed of the organization, the child becomes a communicant or member of the church body with the full responsibilities of an adult member. This initiation usually occurs at a ceremony that includes certain rituals unique to the particular religious body. For many it is a time for the "first communion." It represents a full sharing of the organization's beliefs. Other ceremonies of full membership like bar mitzvah and confirmation acknowledge the ability of the young church members to fully comprehend, embrace, and defend the tenets of the religion.

Marriage. As children mature, they put more distance between themselves and their parents. They spend less time at home, they learn to enjoy the companionship of agemates, and they enjoy their own independence. The majority decide to make a new family with someone they have come to love. Many persons seek the blessings of their religious organization in this union. All religions have rituals to consecrate such unions and to provide for the entrances of new members into their denomination. Again, families turn to their religious organizations at this milestone, and together they help their children enter this new life stage.

Death. The goal of most religions is to prepare their members for death and an afterlife. Thus, it is natural that religious organizations have developed often elaborate ceremonies and rites of passage to support the dying person and the person's family and friends. Last rites mark the entrance of the dying person into this final stage, and these rites help family and friends cope with the death of their loved one, as well as contemplate their own mortality.

The major life stages marked by the church ceremonies of baptism, full membership, marriage, and death, are not unique to the experiences of persons who are members of religious organizations, but are stages that are closely aligned with the beliefs, doctrines and missions of these groups. Organizations and families use these ceremonies to observe these changes across the life span, and religious organizations have developed ceremonies and rites of passage that enable members and their families to celebrate these joyous milestones, and to accept and understand the meaning of the sorrowful ones.

When a child is handicapped, he or she is often unable to participate fully in these ceremonies, or participation may be delayed. In this respect, these religious milestones may reinforce the parents' sadness and disappointment that their child cannot fully enjoy all of life's opportunities. Yet these ceremonies may also offer comfort, as when the child is baptized and welcomed into the congregation without regard for the child's disability.

④ *Rituals and Corporate Worship.* Religious organizations have predictable patterns to their formal meetings--the Catholic Mass, the prayer meeting, the church or temple service. Members often come to expect the rituals associated with church services, and frequently are perturbed if church leaders deviate from the traditional forms. Many rituals take on symbolic functions and are perceived at times as the experience they represent. When the ritual is not a part of the worship service, the "experience" for some members did not occur. When asked about her attendance at church, one mother said: "I don't feel guilty when I miss, but I do miss it." When queried further, she explained "it" as "the rituals." She said, "It doesn't matter which parish church I attend, I will get the same feeling--I derive strength from the rituals."

Rituals and group worship experiences embody a form of supportive structure that some people find meaningful. For many it is a tie to the past, and through participating in events that were a part of their lives as children, they experience a comfort, aptly referred to in some circles as "mother church."

Support also comes from a religious organization's stated principles or beliefs that are central to the organization in the forms of written scriptures, creeds, and doctrines. As noted earlier, these principles are taught to members and are reflected through prayers and rituals. The beliefs provide the organization's interpretation of the nature of the universe, and offer explanations for what happens to people and why. This framework for understanding the world helps members answer questions that seem to many to be "unanswerable." Members can recall the scriptures, for example, to compare how another person responded to a difficult situation, and to find an example to follow. Members can derive comfort through acknowledging or confessing mistakes and violations of the rights of others. Likewise, members can feel thankful when good things happen to them, as their belief system has taught them how to interpret such experiences and how to make appropriate responses under such circumstances. For many, these creeds are accepted on faith and therefore they need not be questioned. Armed with the comfort of these answers, one may not have to seek other explanations or answers for life's happenings.

Beliefs: Their Sources and Support

Throughout the life span, human beings strive to understand their existence. Age, mental prowess, environmental stimulants, cultural and physical conditions, and a host of other variables contribute to the questions and the answers that emerge in this continuing search for meaning, which is not restricted by culture, space, or time, but is influenced by these elements. The outcome of this search is the conviction that certain things are true or real. These beliefs may be unformulated assumptions about how and why things are as they appear to be, or they may be highly organized in creeds, doctrines, or tenets of faith that are set down in both written and verbal forms. As discussed earlier in the section on religious organizations, beliefs can be so highly personalized that an individual may not acknowledge that others share them, or beliefs can be widely held tenets that one holds in common with many others.

Beliefs, whether they are individual personal values or tenets one shares with others, play an important role in one's life. Beliefs provide individuals with a framework for living and for understanding life. Beliefs help persons determine how they will live, what they will do with their lives, how they will spend the hours of each day, what and when they will eat, how they will relate to other human beings, and in some cases, beliefs determine where one will live and die. Man, unlike other species, has the ability to think, to analyze, to experiment, and to learn from experiences. Man is not simply a passive recipient of environmental experiences but is a dynamic being, who contributes to his own development, to the development of others, and to the organization of the world around him. Because beliefs are so central to the formation of who and what man is, they serve as supports for the maintenance of life.

Many factors contribute to the beliefs a person espouses at a given point in time. Young individuals are likely to assume the beliefs of other family members. Certain beliefs about the world may be transmitted across generations both in word and in deed. Also influencing one's beliefs are the social institutions one experiences. The educational system, the religious organizations, the interactions between neighbors, the parents' attitudes toward systems, policies and people will have a definite impact on their children. As children move across the life span and become independent, they take more responsibility for their own belief system. For some, this may mean a more clearly articulated profession of beliefs espoused during youth. Others may come to embrace a system of beliefs that is quite different from that they held when they were young. Education, experiences, and exposure to other persons, doctrines, and societies are likely to influence the beliefs or personal values that emerge during the adult years.

Another important source of beliefs is the specific doctrines and creeds of religious organizations. These institutions usually have written documents that are considered sacred, such as the Bible or Torah. Additionally, organizations have canons and other writings that embody beliefs specific to the particular organizations. Some members of religious organizations strictly adhere to all the organization's beliefs and use these beliefs to answer difficult questions about existence, and to help them cope with events in their daily lives.

Many persons are guided by beliefs that are not identified with an organized religious body, although these beliefs have to do with moral codes that are addressed in the doctrines of religious organizations. These spiritual or personal beliefs often are influenced by the religion an individual was exposed to at an earlier life stage. Individuals who leave a church group may continue to live by that religion's code of beliefs, which continues to represent the person's convictions about life and orderliness in the world. For example, an individual may continue to believe in a spiritual being and to turn to that being for strength and comfort without acknowledging the relationship between that source of support and an organized religious body.

Thus, there are many ways in which personal beliefs function as extremely important sources of support for persons in their daily lives. When stressful events occur, beliefs, particularly those that are spiritual or religious in nature, seem to be especially valued. Some persons derive additional support from a religious organization that includes persons with similar beliefs. As Fewell's study indicates, these two types of support may not overlap, and each can stand alone as a coping support.

Beliefs As a Support for Parents of Handicapped Children

Beliefs, regardless of their origins, appear to be particularly important to persons who face stress due to events they did not expect, or can not easily explain. As Fredrich et al. (in press) noted, the stress created by a mentally retarded child can be mediated through religious beliefs. This is so often seen by professionals as parents grapple with the personal question of "Why did this happen to me?". Given that almost all parents of handicapped children face this question, it is appropriate that we explore what it means and how some parents have answered it.

Invariably one of the earliest questions parents ask when they learn their child has a serious impairment is "Why." If a natural cause-effect relationship exists between the handicap and some identifiable event, some parents may end their questioning. Many parents, however, will continue to ask "Why" even after they have found a cause. Sooner or later, the more general "Why" question becomes more personal: "Why did it happen to me?" This question represents a shift in the parent's perspective, as the parent moves from focusing solely upon the impact of a handicap on the child to questioning how that handicap reflects upon the parent, and the effect it will have over the parent's life.

Kushner (1981) reflected on what went on in his mind when the doctor told him and his wife that their child had progeria, a degenerative condition characterized by premature aging and death. What he was facing contradicted everything he had been taught about God. He said:

> I could only repeat over and over again in my mind, "This can't be happening. It is not how the world is supposed to work." Tragedies like this were supposed to happen to selfish, dishonest people whom I, as a rabbi, would then try to comfort by assuring them of God's forgiving love. How could it be happening to me, to my son, if what I believed about the world was true? (p. 3).

The parent who learns that his child is impaired will inevitably ask these questions, just as Rabbi Kushner did. If a parent believes in a creator of life, a God, or God-like spirit, then the question eventually becomes "Why did God give me this child?"

For many parents, the answer to this question is that the child's disability is a form of punishment for a parent's sin. This type of answer reflects a certain understanding or theory of the world and how it operates. If a parent believes that bad behavior results in bad consequences, the child's handicap may be seen as a punishment. The parent's reasoning is, "I have done something very bad." This conclusion can come from one's personal belief system, or from beliefs espoused by one's religious organization.

Whether a parent understands the world in this manner or not, this perspective is so widespread that a family member, friend, or stranger with well-meaning intentions, is likely to imply that the child's handicap must be somehow the fault of the parent. Oosterveen (1979), a chaplain and parent of a retarded son, notes, "I have heard it too frequently to be amazed any longer when parents tell me their friend or neighbor has urged them to 'repent, so God can forgive you and heal your child'" (p. 22).

This is one type of thoughtless response parents often experience from persons who regard the child's handicap as somehow the reflection of the parent's sins. Parents often encounter another response from individuals who attempt to comfort the hurting parent by explaining that "God only sends special children to special parents." One parent related such an experience to the author.

> The first words out of our parents' mouths when Philip was born was something to the effect "It's God's will you have been chosen, and we will pray for your strength."

Particularly distressful are poems that are circulated among parents of handicapped children that have as their theme the idea that the handicapped child and family were selected by God. Oosterveen and his wife, like so many parents of handicapped children, received the following poem from a well meaning person who probably believed the sentiments expressed in the poem would console the parents.

Heaven's Very Special Child

(by Mrs. John A. Massimilla, as cited in Osterveen, 1979)

A meeting was held quite far from earth.
"It's time again for another birth"
The angels said to the Lord above.
"This dear little child will need much love;
His progress on earth may be quite slow;
Accomplishments great he may not show,
And he will require some extra care
From the folks he meets on earth down there.
He may never run or laugh or play;
His thoughts may seem odd and far away.

In various ways he won't adapt,
And he will be known as handicapped.
Please, Lord, find some parents for this child
Who'll do this work as unto You.
They'll not understand it right away,
The difficult role You have them play;
But with this dear child sent from above
Comes strength and new faith and richer love.
And soon they'll know the privilege given
To care for this gift that's straight from heaven.
This precious young charge so meek and mild
Will always remain Your Special Child."

Oosterveen, speaking from his background as a theologian, goes on to explain his deep concern with the sentiments expressed in the poem, no matter how well intended: "Besides violating biblical teachings under the guise of poetic license--nowhere is such a meeting described, nor does Scripture permit us to assume handicapped children come to us from a different place or through a different process than normal children--the poem abuses parents at the very time they suffer what may easily be the most traumatic experience of their life (p. 22).

Another minister of the Mennonite Church, whose son Scott has Down syndrome, also received three copies of the poem. He has also spoken out on the stereotypes of handicapped children the poem contains, and on how little it helps parents understand why this has happened to them.

> In dealing with our personal circumstances we have come to believe that God does not will the tragic birth of children like Scott ... [whose] particular handicap is due to a genetic disorder which scientists cannot fully explain yet. We do not believe that God should be held responsible for this genetic "malfunctioning" beyond the natural laws of genetic development which he created but which were, in Scott's case, violated. We believe that God cried with us over the unexplainable mistake that occurred in Scott's prenatal development. In this respect, the idea expressed by the poet that God and his angels come together to pick us as Scott's parents is inconceivable to us and, with all due respect, slightly offensive (Klassen, 1984, p. 50).

It should be noted that other parents have reported that they have found comfort in the sentiments expressed in these poems.

The idea that a parent has been especially chosen for this role permeates the reasoning of one mother interviewed for this chapter. This mother of a severely handicapped child expressed her family's perspective on the handicapped child in their family:

> My parents feel that God has chosen me to have a handicapped child as a challenge to my religious beliefs and to remind our entire clan to stop and take stock of how very good God has been to each and every one of us.

She added later, "If I didn't have my religious base to keep me going, I'd be nuts by now." Two things are clear from her responses. First, the role of parents and extended family members in helping one "understand" or answer the "why" question is apparent. Many new parents from years of habit and experience continue to look to their parents for wisdom and answers. The idea is that "If one's parents say it, it must be true." Second, this mother has apparently accepted and incorporated that answer into her belief system, and that system is helping her cope.

If the framework of the chosen parent is not one that is acceptable to a family, then what might foster understanding and value clarification? Honest and cautious admission that "some questions have no answers" (p. 25) is suggested by Oosterveen (1979) to members of his own faith who wish to comfort parents and help them cope with their adversity and suffering: "... strong faith and deeply-rooted religious habits are great assets, but no guarantee that parents [of the handicapped] will escape the feelings of depreciation, failure, and shame" (p. 24). The experience always makes a difference in one's life--one is never again the same. The struggle and pain in Oosterveen's mind "lead to a challenged and changed view of God and his dealings with the world." (p. 24)

In grappling with the agony of understanding why a loving, all-powerful God allows bad things to happen to good people, Rabbi Kushner also came to a new understanding of God. First, he had to let go of an image of God as responsible for all things that happen. He says:

> The conventional explanation, that God sends us the burden because He knows that we are strong enough to handle it, has it all wrong. Fate, not God, sends us the problem (p. 129).

He goes on conclude:

> God does not cause our misfortunes. Some are caused by bad luck, some are caused by bad

> people, and some are simply an inevitable consequence of our being human and being mortal, living in a world of inflexible natural laws (p. 134).

By stopping to regard God as the cause of misfortunes, Kushner did not have to feel angry at God for having betrayed him; rather he could turn to God for help, strength, and perseverance in overcoming his hurt and anger. This enabled him to move on to a more relevant question:

> Now that this has happened, what shall I do about it? ... Not "where does the tragedy come from?" but "Where does it lead?" (p. 137).

In addressing the why question, the answers that Oosterveen and Kushner give reflect strongly the support they experience from both their religious organizations and their personal beliefs. Of particular interest are the changes that both members and teachers of church organizations experienced in their belief systems. In both cases, it is apparent that their beliefs have provided valued support in coping with these stressful events.

Conclusion

In this chapter we have examined the support religious organizations and personal beliefs offer to parents as they carry out their parenting responsibilities for a child whose abilities and potential are quite different from what the parents had anticipated, resulting in greater stress for their family. The nature of religious organizations and of personal belief systems suggest why these supports are so highly valued: both types of religious support help persons deal with the fundamental questions of life. By providing answers, regardless of their specificity or truth, these support sources help parents to get on with their lives, to attend to other things besides the stressful experience, and to discover new things about themselves and their world. For some parents, religion provides support directly related to the parent's role as a member of a religious group. For other parents, support comes from both the contributions of the group and the beliefs which group members share. Yet for other parents, support is provided by their personal belief systems. One thing, however, is clear: for far too long, professionals who work with families of handicapped children, including professionals associated with religious organizations, have failed to understand and realize the importance of these sources of religious support. Although neglected or rarely taken seriously by professionals, it has not been overlooked by parents, and from these sources they often derive much of the strength they need to nurture their child with special needs.

Table 1

Religion Scale

ems	Category	0 10 20 30 40 50 60 70 80 90 100
Our clergyman was helpful to us when our handicapped child was born.	N/A	34.2
	Agreed	41.8
	Neither	7.6
	Disagree	16.5
We are satisfied with availability of religious instruction for our handicapped child.	N/A	29.5
	Agree	32.0
	Neither	21.8
	Disagree	16.7
We are more active in our church since our handicapped child was born.	N/A	19.5
	Agree	13.0
	Neither	26.0
	Disagree	41.6

Items	Category	0 10 20 30 40 50 60 70 80 90 100
4. If we had problems associated with our handicapped child, we would seek help and guidance from members of our church or clergy.	N/A	18.2
	Agree	37.7
	Neither	13.0
	Disagree	31.2
5. The church has been more supportive to us than other agencies in our community by providing the help we need as parents of handicapped child.	N/A	21.5
	Agree	13.9
	Neither	25.3
	Disagree	39.2
6. Most of my social activities involve members of my church.	N/A	20.3
	Agree	32.9
	Neither	7.6
	Disagree	39.2
7. Our religion has helped us to understand and accept our handicapped child.	N/A	15.6
	Agree	66.3
	Neither	10.4
	Disagree	7.8

Items	Category	0 10 20 30 40 50 60 70 80 90 100
8. We are satisfied that our religion is fulfilling our family's spiritual needs.	N/A	12.7
	Agree	59.5
	Neither	16.5
	Disagree	11.4
9. Having a handicapped child has brought us closer to God and our religion.	N/A	10.3
	Agree	55.2
	Neither	24.4
	Disagree	10.2
10. We seek comfort through prayer.	N/A	7.7
	Agree	75.6
	Neither	9.0
	Disagree	7.7
11. Our faith continues to be a source of help and support in coping with our handicapped child.	N/A	10.3
	Agree	70.5
	Neither	11.5
	Disagree	7.6

Items	Category	0 10 20 30 40 50 60 70 80 90 100
12. Our faith is a source of personal and family strength to us in everyday living.	N/A	8.9
	Agree	69.6
	Neither	11.4
	Disagree	10.1

Table 2

Means, Standard Deviations, Differences and t Values for Organized Religion and Personal Beliefs Scales (N=78)

Scales	Mean	S.D.	t	P
Organized Religion	13.22	7.75		
Personal Beliefs	21.85	8.44	-.1308	.000

Table 3

Percentage of Responses to Questions on Support from Organized Religion and Personal Beliefs

	Not Applicable	Neither Agree or Disagree	Agree	Disagree
	%	%	%	%
Statements Indicating Support From Organized Religion	24	17	29	31
Statements Indicating Support From Personal Beliefs	11	14	66	9

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A HANDICAPPED CHILD IN THE FAMILY

REBECCA R. FEWELL

IN: FAMILIES OF HANDICAPPED CHILDREN:
NEEDS AND SUPPORTS ACROSS THE LIFESPAN

Prepublication Draft

A HANDICAPPED CHILD IN THE FAMILY

Rebecca R. Fewell

A basic premise underlying this book is that families are the most appropriate agents for transmitting basic human competencies to their children. The authors in this volume attest to the important role played by extended family members and community agencies to support the primary or nuclear family in carrying out their caregiving tasks. These assumptions remain true regardless of family members' economic status, cultural preferences, political leanings, or their physical, mental, or emotional states. When families have members with very special needs, all family members and community agencies will be affected. There is no fail-safe plan which a family should follow. Each situation is unique. Nevertheless, much information exists on common concerns and problems, and the processes and solutions that have enabled families and agencies to support the handicapped person in reaching his or her fullest potential.

THEORETICAL PERSPECTIVES ON THE ECOSYSTEMS OF FAMILIES

Throughout history and across cultures, the family has been the primary agency for survival. Although the forms of families vary, the tasks are universal. Parents or parent surrogates across all cultures assume the responsibility for transmitting to their offspring the competencies required by the social, economic, and political forces of their society or social group.

Family members do not operate in vacuums. Members are influenced and changed by other members, and by the circumstances in which they exist. If society's goal is to help families carry out their caregiving tasks, then it is necessary that we understand the influences that family members and their environments have on one another. To do this, it is helpful to examine theories of family interactions that include an ecological perspective. The ecosystem approach is broad based and includes family, peers, and all persons having a significant effect on a child's behavior (Salzinger, Antrobus, and Glick, 1980).

A number of theorists (Belsky and Tolan, 1981; Bronfenbrenner, 1977, 1979; Sameroff and Chandler, 1975; Thomas and Chess, 1977) have described models to convey how family interactions evolve, and have included their perceptions of the impact of a family member with special needs. Sameroff and Chandler (1975) and Sameroff (1980) describe the transactional model that reflects a linkage between risk factors and developmental outcome, resulting "from a continual interplay between a changing child and a changing environment as the child entered higher levels of cognitive and social functioning " (p. 345). In this model, the environment is the only accountable reason for deviance in the more mature levels of functioning. Sameroff (1980) noted a caution concerning the limitations of the transactional model for studying certain situations such as those in which a major restriction or physical deviancy exists. Such aberrations are unusually strong factors that produce impacts greater than many environmental variables, and as a result, justify the use of a single factor or interactional model. Examples of such powerful single factors are deafness, blindness, and other handicapping conditions. He summarizes,

> a transactional model is needed to explain development in environments that are sensitive to and can compensate for early deviances so that they are not transformed into later deficits. However, when the range of environments is restricted, either through ignorance or choice, outcomes can be found which appear to be additive or produced by single risk factors taken alone (p. 346).

If we use this model to examine dyadic transactions involving parents and a child with an impairment, a parent's actions are seen to influence the child's behavior, and the child's actions change the parent's behavior; however, the contribution of the impairment to the transactions between parent and child may be so strongly influenced by the impairment that this single factor accounts for the quality of the transactions between the parent and child. The conclusion drawn by Korn, Chess and Fernadez (1978) from their in-depth study of 243 children with rubella syndrome and their families supports this assumption: "The impact of the child on the family appears to be more related to the characteristics of the rubella children, with their wide variety and number of handicaps, than to the attributes of the parents" (p. 324).

A similar paradigm has been described by Thomas and Chess (1977) as the "goodness-of-fit" model for adaptive development. This relational, person-context match model permits the examiner to predict outcomes. If a child's individual characteristics match the demands of a particular setting, adaptive outcomes accrue. In contrast, mismatched children, whose characteristics are incongruent with the setting, can be expected to develop alternative outcomes. This model helps explain why children with very similar conditions have extremely different outcomes.

Likewise, Belsky and Tolan (1981) subscribe to the principle that, under most circumstances, development is the product of the complex and continuous interaction between an ever changing organism and his or her environment. However, like Sameroff and

Chandler (1975), Belsky and Tolan feel under certain conditions "(e.g., severe anoxia in the post partum period), it is likely that some developmental possibilities (e.g., normal intellectual functioning) will be foreclosed" (p. 110). In such cases, subsequent behavior is a reflection of these earlier experiences.

The concerns of Sameroff and Chandler and of Belsky and Tolan about the impact of certain conditions are reflected by Wohlwill (1979), who describes developmental continuities and discontinuities as dependent upon the continuity and discontinuity of the environment. These concerns have been clearly demonstrated in the studies of Waters (1978) and Vaughn et al. (1979). Waters observed marked stability in the attachment (to mother) ratings of 50 middle-class infants between 12 and 18 months of age. However, when Vaughn et al. examined a larger sample of lower-class infants, the results were not replicated. Internal analyses revealed that the infants who showed unstable attachment classifications across the 6-month period were likely to have undergone several major environmental disruptions.

From these perspectives, development, both biological and social, is seen as a process of continual adaptation due to the constant states of change in the individuals and the environment. The accommodations of individuals are always short-lived because of the progressive and transactional nature of the process itself. While changes and accommodations are inevitable and indeed essential, extreme situations and events can create a discontinuity that affects the entire ecosystem, requiring a closer examination of transactions in order to support families in their predestined roles. Fortunately, many ecosystems are inhabited by persons with remarkable plasticity, from whom far more is possible than can be dreamed, particularly when they face the challenge of caring for a vulnerable child.

The Nurturing Mission

A universal role of families is to nurture the young child. The family provides for the child's physical needs, and fosters the development of an integrated person capable of living in society and transmitting culture (David, 1979; Lidz, 1963). Parents foster the child's competence, defined by Ogbu (1981) as "a set of functional or instrumental skills" (p. 414), derived from culturally defined adult tasks. Connally and Bruner (1974) distinguish between specific and general competency skills but stress the latter. General skills reflect operative intelligence, the "knowing how" rather than simply "knowing that," while other general skills are related to emotional, linguistic, and practical considerations. These skills make up what the authors have described as the "hidden curriculum in the home" (p. 5) and are those skills essential for coping with existing realities. A person's ability to function is related to how well he or she masters these competencies.

These theoretical perspectives suggest that some children fail to develop appropriate competencies for later success in society because they have impaired systems and their learning abilities are not sufficient to enable them to achieve the societal expectations. Other children fail because the parents failed in their child-rearing tasks. At times, parents' failures can be traced to the lack of support available to the parents from their extended families or their community agencies. Success or failure does not have to be limited to one cause, but can be due to a combination of factors transacting at a given point in time, a testimony to the complexity of the human situation.

The nurturing mission of adult family members for their young is difficult yet joyous. The presence in the family of a child with special needs requires more effort from the other family members; yet in giving more, family members become eligible for more intense experiences -- of pain as well as pleasure.

Family Supports

To simplify our writings throughout this book we will assume that a family is a group of two or more people that, in our case, includes at least one parent or parent substitute, and one handicapped child related by blood, marriage, or adoption. These persons constitute a family system by virtue of the fact that they bear a definable relationship to one another (Geismar, 1971). The family is greatly influenced by persons outside the immediate nuclear group. Extended family members and other kin, neighbors, and co-workers, are supportive agents. Additionally, support is also rendered through less personal connections such as institutions, agencies, and governmental policies. Unger and Powell (1980) described three types of support provided by social networks: (a) instrumental support, (b) emotional or social support, and (c) referral and information. Networks provide different types of support. In this section we describe three social support systems, and examine the types of support each provides when a nuclear family has a handicapped child.

Spousal Support. In a recent survey of 80 mothers of children with Down syndrome, mothers indicated spouses to be the most important of 19 possible support persons (Fewell, Belmonte, and Ahlersmeyer, in preparation). Similar findings on the same scale were reported by Dunst, Trivette, and Cross (in press) in a study of Appalachian parents. Vadasy and Fewell (Chapter __) report similar findings when mothers of deaf-blind children were surveyed. Crnic et al. (1983) in their study of mothers of premature infants found that intimate support had the most positive effects on mothers' attitudes and behaviors. Spouses share in the emotions, the physical care, the nurturance, and the concerns about the future. They can listen to one another, cry, laugh and play together. The mutual support that parents provide each other is important, since there is evidence that the presence of a handicapped child affects marriages one way or another. Gath (1977) studied marital stress by comparing 30 parents of children with Down syndrome to 30 matched parents of normal children. While a number of differences were noted in the 5-year study, marked differences were present in the quality of the parents' marital relationship. Marital breakdown or severe disharmony was found in nine of the families with children having Down syndrome, but in none of the controls. Yet on the other hand, positive measures were also higher in the families that had Down syndrome children. These parents felt drawn closer together and strengthened in their marriages by their shared tragedy, a view also reported by Burton, (1975). On the other hand, in D'Arcy's (1968) study, 73 of 90 mothers of children with Down syndrome claimed their marriages remained happy or unchanged after the child's birth. Friedrich's (1979) finding that marital satisfaction was the single best predictor of a family's positive coping behavior when rearing a handicapped child supports the importance of the spousal relationship to total family adjustment.

Support from Other Children. Families report their other children are very important to them in the care of their handicapped child. Older daughters are apparently given more responsibilities in caretaking roles. Fowle (1968) like Gath (1973, 1974) found the oldest female to be more adversely affected by the presence of a retarded child in the home than was the oldest male sibling. In their study of mothers of deaf-blind children (Vadasy and Fewell, Chapter ___), mothers most often indicated that their daughters were the second-most important source of support, while sons were listed as the third-most important source of support by 10 percent of the respondents.

Kinship Networks. Grandparents play very important roles in the lives of grandchildren, both in terms of their personal interactions with the handicapped child and in their support to the child's parents. Grandparents are available to help with child care, and provide material, psychological, and emotional support. Uzoka (1979) and Sussman (1959) have presented evidence that kinship networks are active despite geographical separations. Extensive intergenerational relationships abound across class and cultural differences. Caplan (1976) described nine supportive characteristics of family and kin systems: (1) collectors and disseminators of information; (2) feedback and guidance; (3) sources of ideology; (4) guides and mediators in problem-solving; (5) sources of practical service and concrete aid; (6) a haven for rest and recuperation; (7) a reference and control group; (8) a source and validator of identity; and (9) a contributor to emotional mastery.

The kind of support an individual derives from family may be related to physical proximity, although face-to-face contact is not required to sustain the relationship (Litwak, 1960; Troll, 1971). Relatives who live close to each other aid in the care and supervision of children (Caplan, 1976; Sussman, 1959) and house maintenance tasks (Sussman and Burchinal, 1962). Resource exchanges (e.g., gifts, clothes, household items, and money), shared social and recreational activities, and psychological and emotional supports commonly strengthen bonds between kinship network members (Sussman and Burchinal, 1962). Cohler and Grunebaum (1981) found the telephone to be an important linkage between family members. Given the importance of kinship support, it is logical that a nuclear family will reach out to members of this network when faced with a situation that is stressful or requires more resources than they have at hand. Schell (1981) eloquently decribes the family support that enabled him and his wife to get a more stable perspective on their emotions, integrate their feelings about their infant daughter who had Down syndrome, and begin a plan of action to optimize her development. Schell points out that often one member of the family offers special support, and in his case it was a sister-in-law, "Aunt Cindy." Schell's worries and fears about the future were significantly allayed by family support: "Cindy's remaining an energetic force in our lives, as she was before Christina's birth, has helped us to feel like any family with caring and sharing relatives" (p. 25).

Friends, Neighbors and Co-Workers

McAdoo (1978) examined family support systems and found friends ranked second in importance behind kin. Friends and neighbors provide a important source of support with short-term assistance such as babysitting, meals during an illness, and care of property in one's absence. Gabel and Kotsch (1981) found that family friends and babysitters frequently attended the bimonthly evening clinics the Family, Infant, and Toddler Project held for families of handicapped. Turnbull (1978) tells of a surrogate grandmother relationship that developed between her handicapped son and a neighbor, yet she also laments broken friendships with others due to her son's handicap. The personality and sensitivity of the individual appear to be the critical variables in determining who will be supportive.

Community Agencies and Governmental Policies

A number of agencies offer informational support for families with handicapped children. Most notable of these are advocacy groups such as Associations for Retarded Citizens, Easter Seal Society, Parent-to-Parent groups, Lions Club, etc. These organizations often offer emotional or material support as well. As Fewell describes in Chapter ___, churches and other religious organizations are also important sources of support for families with handicapped children.

Schools, educational agencies, day care centers, and health agencies also provide support that is primarily informational. Public laws such as P.L. 94-142 and numerous court cases (e.g., Armstrong v. Kline, 1979; Pennsylvania Association for Retarded Children v. Commonwealth of Pennsylvania, 1972) have played critical roles in supporting families with handicapped members. Legislation and litigation have opened school doors to all handicapped children, lowered ages for entrance, and provided for parent participation in educational decisions about their child. This kind of support is widespread and long lasting, enabling parents to plan for the future with a greater degree of certainty.

CHILD CHARACTERISTICS THAT AFFECT FAMILIES

A child's particular needs at a given point in the child's life will have an impact on family and community responses. In this section we will consider three major variables that influence the family's ability to adapt: the type of impairment; the severity of the impairment; and the age of the child which is associated with characteristic critical periods of family adjustment.

Types of Impairments

Handicaps can be described as conditions that cause persons to be perceived as different from what others think to be appropriate. According to this view, what is a handicap or who is handicapped is in the eyes of the viewer, and is in reality a value judgment made from the viewer's perspective. Persons will differ in their judgments based on their cultural heritage (Edgerton, 1970), their experiences with similar conditions, and their personal value systems (Pickarts and Fargo, 1971).

Mental retardation. When parents first learn that their child is mentally retarded, they are usually devastated. This is normal, expected, and appropriate. Long-nurtured hopes and dreams vanish and are replaced by fuzzy and distasteful images based on often negative past encounters with retarded persons. Mental retardation, probably the most dreaded diagnosis a parent can receive, carries the stigma of a static condition resulting in a social destiny of isolation, dependency, and institutionalization.

Mental retardation is also a historical and a social concept that sets individuals apart from others. By performance standards, the mentally retarded person is judged inadequate and, according to Sarason and Doris (1979), "this inadequacy is sufficiently troublesome to those in that context to warrant actions to achieve three purposes: to keep performance standards intact, to reduce or eliminate the discomfort of those who are troubled by the individual's inadequacy, and to be helpful to the individual as help is defined by the moral-ethical values of that social context" (p. 38). In describing society's perspective, these authors indicate "the retarded child has always been a second-class human being for whom one should have pity, and toward whom one should be human, but for whom society has no use" (p. 77). The societal definition of mental retardation has changed dramatically over the past 15 years. Through scientific research, we have new evidence that refutes past assumptions about limitations. Through political advocacy, we have legislative and litigative reforms, and emerging is a new social awareness of the meaning of human behavior.

Behavior that is viewed by some to be different at a point in time in a given situation may not be viewed as different by others. While the discriminatory nature of the label is now deplored, society has yet to agree on what constitutes mental retardation. It is defined by the arbitrary criteria of a given individual's behavior at a point in time, and is reflected in the viewer's actions. It is viewed only in the context of a transaction between an individual and his or her ecological milieu. Fortunately, the concept of mental retardation is elusive in time and space, and in the view of many (Gliedman and Roth, 1980; Sameroff and Chandler, 1975; Sarason and Doris, 1979), it must be discarded entirely. Braginsky and Braginsky (1971) are adamant in their position: mental retardation "has no scientific value whatever, merely serving to obfuscate and distort the meaning of the behavior of the rejected child" (p. 176). The label is particularly tragic for families who subscribe to cultural definitions of success which include high expectations for intellectual performance.

Hearing impairments. About 0.075 percent of all school-age children are deaf, and another 0.5 percent are considered hard-of-hearing. Among the leading causes of severe hearing impairments are heredity, maternal rubella, prematurity, meningitis, and blood incompatability (Moores, 1978). Only between 16 and 30 percent of deaf children have deaf relatives

(Reis, 1973). This has implications for the efforts family members must make to learn to communicate with the deaf child.

Hearing impairments alone will not delay a child's motor or cognitive development. However, reduced language experiences affect performances on achievement tests and on some cognitive measures. Deaf children are often socially less mature than their hearing peers, and they are more than twice as likely to have emotional problems as hearing children (Graham and Rutter, 1968; Levine, 1960). Family members are expecially likely to experience the effects of these associated delays and problems as the child grows older.

Visual impairments. Blindness or severely limited vision can be caused by genetic conditions, infections, diseases, or traumatic events. A visual impairment of genetic origin may result in blame or guilt on the part of a parent, or it may result in a parent's understanding and acceptance because of the parent's previous experience with the condition. Adventitious blindness permits the natural family bonds to develop, yet places stress on families to adjust to a permanent change that has far-reaching consequences.

Unlike many handicaps, visual impairments are measurable, and services are likely to be based on legal definitions. However, the most important factor in determining the effects the vision loss will have on the individual is the individual's functional use of sight. The presence of some useful vision makes a big difference in the impact the impairment has on the child and the family.

Blindness from birth results in delays in the development of certain sensorimotor schemes, and in the acquisition of abstract concepts (Fewell, 1983; Fraiberg, 1977; Stephens, 1972). However, Higgins (1973) examined the performance of blind children 5-11 years of age and found no evidence of a general developmental lag. Developmental lags and less efficient movement characterize the motor development of blind children from birth through adulthood (Adelson and Fraiberg, 1974; Norris, Spaulding, and Brodie, 1957). Blindness does not lead to language deficits; however, the blind child's language may be characteristically different in the early years (Landau, 1983; Mills, 1983; Urwin, 1983; Warren, 1977). There is evidence of delayed and aberrant social skills among the blind (Fewell, 1983). However, the way family members relate to the young blind child will have an important impact on the child's social skills and self-concept.

Blind persons are described in the literature, seen on television, and are encountered in our communities. Blindness may conjure images and memories of talented musicians or begging street vendors. Stereotypes of certain handicaps influence how families experience their child's handicap. However, far more formidable in influencing the family's reaction is personal knowledge of a blind person. Knowing that a blind person can think, communicate, and carry on the process of daily living independent of others makes blindness appear less devastating than other handicaps.

Physical impairments. A major physical handicap is cerebral palsy, a disorder of muscle control resulting from brain injury during the early stages of development. The injury is likely to affect several areas of the brain, resulting in multiple handicaps. Between 60 to 70 percent of children with cerebral palsy are mentally retarded, 70 to 80 percent have impaired speech, 50 percent have visual problems, and 35 to 45 percent have seizures (Healy, 1983). Although cerebral palsy may not be detectable in the first few months of life, most cases are diagnosed by 18 months of age.

Physically impaired children's movement activities are most obviously affected by their disabilities. Limited movement is likely to affect the acquisition of self care and social skills. The child's inability to move causes others to lower their social expectations for the child, making the physical disability a handicap.

It should be noted that many children with cerebral palsy have normal mental abilities, and can progress well in regular classrooms if accommodations are made to enable them to participate in the curriculum and activities. When environmental adaptations are made, these children are among the easiest to integrate into regular classrooms.

Other physical impairments such as spina bifida, hydrocephalus, and muscular dystrophy occur less frequently, and present entirely different problems. For example, in muscular dystrophy the child, the family, and friends often face the child's gradual degeneration. Occupational therapy and counseling are important services to help the child remain independent for as long as possible, and to adjust to the condition as abilities fade.

Severity of Impairments

The less serious an impairment, the easier it is for an individual to participate in the everyday activities with his or her peers. More serious impairments often demand specialized medical, educational, physical, and emotional assistance. The involvement and concern of families follow a similar course. Because the severity of an impairment affects the family's reactions and ability to nuture the child, it is appropriate to examine the impact of the severity of the handicap on the child and the family.

Mild impairments. The mild handicaps are often not detected as early in life as more severe and obvious impairments. This fact has several implications for the handicapped child and his or her family. First, because the impairment may not be recognized until the child enters school, the family will have proceeded in their nurturing mission as though their child did not have special needs. If questions do arise, relatives and professionals alike are quick to reinforce hypotheses that involve comparisons to "Uncle Harry" or "all three-year-olds" (Fewell and Gelb, 1983).

Second, mild handicaps are more prevalent and consequently, there are more services available to respond to them. For example, speech clinicians and reading teachers are common in most elementary schools. With the thrust of P.L. 94-142, mildly handicapped children are served in the least restrictive environment possible, and for many of them, this is the regular classroom with services from a resource room, itinerant teacher, or clinician. The presence of the mild problem may be known to those children in the child's immediate education environment, but seldom known to others in the school or neighborhood setting.

Third, parent reactions to a diagnosis of a mild handicap such as a learning disability are varied. Osman (1979) reported parents of children seen in her diagnostic clinic for learning disabled children go through emotional stages similar to those experienced after a severe loss or death in a family. The invariable set of first questions can be expected. Osman refers to a learning disability as "a family affair," suggesting its widespread effect on all family members. The effects of such impairments are often limited to situations in which the child must respond to predetermined stimuli in set ways. When learning disabled children are able to adapt solutions to their own learning style, they are often able to compensate for their problems, and others may be completely unaware a problem exists. In the post- school years, mildly handicapped persons are candidates for jobs that are not stressful, given their limitations, and that match the expectations of their age group. Once this occurs, parents and family members are often relieved of the stresses they experienced while the child was in the learning environment.

Moderate impairments. Persons with moderate handicaps are sometimes perceived as "normal," and at other times viewed as "abnormal." The situational context determines both the performance of the handicapped individual as well as the perceptions of those surrounding the person. As Fewell and Gelb (1983) have indicated, the ambiguity of this situation has implications for both the handicapped person and for the family. According to Stonequist (1937), the marginal person is one who may claim membership in two worlds, but who is not completely at home in either world. At times the person seems to belong to the nonhandicapped world, while at other times the person is grouped with the severely impaired. This dilemma creates continual psychological stress, as both the handicapped person and his or her family must determine how the persons in the particular environment are perceiving them, and then choose how to adapt to the situation. Gliedman and Roth (1980) illustrate the curse of marginality so poignantly in their classic book, The Unexpected Minority. In presenting the stress this duality places on the handicapped person, they write:

> Lurking behind the decision to 'pass' are its potential costs--costs that sometimes include the possibility of bad faith. Passing requires time and energy. It requires ingenuity and usually subjects the individual to considerable emotional strain. Most of those who pass successfully live in constant fear of being found out--e.g., the child with a reading disability, the adult who has spent time in a residential institution for the mildly retarded, the child with a chronic illness such as epilepsy which many consider to be shameful, the adult with a concealable defect or disease that exerts an influence upon his fears that is out of all proportion to able-bodied society's attitudes toward the disability. Most crucially of all, passing undermines the self's sense of authenticity and genuine worth. I seem to be a regular guy or a normal kid. But is

> this able-bodied person, this careful fabrication, the real me? And if I must always dissemble to hide my handicap, who is the real me? Am I leveling with myself, or am I acting in bad faith? Passing is a kind of social 'white lie'--perfectly understandable yet unpredictable in the devastation it may wreak on an individual's ability to know where the mask leaves off and the true person begins. Insecurity, rigidity, extreme conformity, and overdramatization of the role one assumes are among the occupational hazards of the individual who successfully passes (p. 85).

Parents of moderately impaired children are likewise faced with stress resulting from society's view of their child. Parents will strive to help their handicapped child adapt to the impairment and to society's expectations of nonhandicapped persons, yet at the same time, they are members of the society that condones the handicapped person's need for additional support services. In recognizing and openly supporting their child, family members are frequently viewed as if they too are handicapped, a concept described by Goffman (1963) as a "courtesy sigma." Turnbull and Turnbull (1978), Darling (1983), and Paul and Beckman-Bell (1981) cite many examples of situations in which parents are made to feel as though they too are part of their child's problem.

Severe impairments. Severe handicaps are usually identified much earlier in life than are mild or moderate handicaps. Many are recognizable at birth. The diagnosis is always a source of great sadness, and the hurt is felt by all the family, friends, neighbors, indeed, by everyone who knows the family. Rosen (1955) has noted that parents react to the birth of a handicapped child in a fairly predictable manner, and move through the following stages of adaptation: awareness of a problem, recognition of the problem; search for a cause; search for a cure; and acceptance of the problem. Roos (1963), the father of a handicapped child, relates the more individual and intimate emotions parents experience, noting a loss of self-esteem, shame, ambivalence, depression, self-sacrifice, and defensiveness. While such negative reactions characterize many of the earlier studies, it is indeed encouraging to see more recent studies examining families' positive coping strategies and reporting the effectiveness of intervention in significantly reducing stress, feelings of inadequacy, guilt, and increasing self-esteem (Vadasy et al., 1984).

While severe handicaps are initially shocking and a source of ongoing stress, parents can benefit from factual information which helps them understand from the beginning what the family and the child will face. Accurate information reduces ambiguity and enables parents to begin as early as possible to plan for their child's future, as Schell (1981) described. Parents who are thus prepared are less likely to experience the confusion created by the ambiguity of many mild and moderate handicaps. It is clear that the severely handicapped child will need services, and will need them throughout his or her lifespan. Parents who accept this fact can prepare themselves to assume an advocacy role. Parents of severely handicapped children will need to plan more extensively for their child's future, as it may be clear that independence is simply not possible for the child.

Child's Age and Predictable Crises

All families share certain critical experiences as their child grows up. Satir (1972) refers to these as major, natural, and common steps that create at least temporary anxiety before readjustment takes place. When the child grows and develops and matches the cultural expectations associated with these periods, family members experience satisfaction and associated feelings of accomplishment.

Children with handicaps will be slower accomplishing these milestones, however, and some may never achieve them. As the handicapped child approaches these critical periods, the parents may experience renewed sorrow and apprehension as they compare what is with what might have been. Six events or periods that are often stressful for the family with a handicapped child are briefly described, as well as some of the expectations that handicapped children fail to meet during these crises periods, and how the child's development contributes to family life and health.

Learning About the Handicap

The nature of a handicap has much to do with when parents learn about their child's handicap. When a handicap such as Down syndrome or Tay Sachs has a genetic origin, parents are usually informed within a few days of the child's birth. Deafness, physical impairments, and language and learning disabilities are examples of handicaps that may not be discovered until the child is older. The confirmation that there is a serious and enduring problem is always a crisis and affects all family members. The immediate reactions of sadness, grief, and disappointment are normal and expected. Although as time passes, parents begin to understand the meaning and implications of the child's handicap, pain lingers, and feelings of confusion, anxiety, anger, avoidance, denial, and rejection often recur. For some families, this initial crisis may be experienced as a time of sharing, support, and commitment from family members and others.

All human infants enter the world in a totally dependent state. While physically impaired infants may require some additional care, their needs are still virtually the same as those of nonhandicapped infants. In many ways, this is the period when the family's care and treatment of their handicapped child is most normalized, and when society is least likely to stigmatize or call attention to the child's differences. Mothers of handicapped infants as well as mothers of nonhandicapped infants share basic caretaking concerns like how to prevent diaper rash, what kind of pacifier to provide, or what kinds of foods to introduce. These common concerns can help the mother of the handicapped child feel less isolated and appreciate the many ways in which her child is like agemates.

Seeking Special Help: Early Childhood

Once children can walk, can feed themselves, are toilet trained, can verbally express their needs and feelings, and can entertain themselves for brief periods of time, parents experience relief, and a sense of satisfaction at having helped their child achieve these important steps towards independence. If a child's impairments are such that these milestones are considerably delayed, it is quite obvious that the caregiving responsibilities of the family members will be extended in time, and that increased physical and emotional effort will be required to continue the caregiving routines. The task of diapering a 3-year-old is simply not as easy as it was when the child was one year old. The larger and heavier child requires more energy to lift and carry. The emotional burden is also great: parents anticipate the end of diapers and two o'clock bottles, and when these things don't end, it shatters dreams and invites questions about the future. Featherstone (1980) described this fear:

> I remember, during the early months of Jody's life, the anguish with which I contemplated the distant future. Jody cried constantly, not irritable, hungry cries, but heartrending shrieks of pain. Vain efforts to comfort him filled my nights and days. One evening when nothing seemed to help, I went outside, intending to escape his misery for a moment, hoping that without me he might finally fall asleep. Walking in summer darkness, I imagined myself at seventy, bent and wrinkled, hobbling up the stairs to minister to Jody, now over forty, but still crying and helpless (p. 19).

For many families, a crisis occurs when they seek, then find an agency that can provide their child with early intervention services. A crisis may ensue for a number of reasons: 1) parents see older children with the same impairment and get a glimpse what their child may be like in a few years; 2) parents become aware that the services their child needs may present a financial drain, or may require time commitments or conditions they had not anticipated; 3) parents who begin to share their experiences with other parents may realize they may need to advocate to get the services their child needs; and 4) parents learn they are expected to be their child's primary teachers as well as caregivers and nurturers. Parents may find that professionals treat them as patients who need treatment (Seligman, 1979; Turnbull and Turnbull, 1978) rather than as experts in their own roles as careproviders. As parents begin to realize what education and therapy services mean, and what a major focus these services will be for their family for the next 21 years, they may feel helpless and overwhelmed.

Entrance into Public Schools: Middle Childhood

When the handicapped child fails to fit into the mainstream of the traditional educational system and requires special schools or classes, a separate transportation system, and a very special curriculum, parents are again confronted with their child's differences and can be very sad. By the time the child is school age, more persons are likely to be aware that the child is different. Siblings may find this to be a very difficult time. As more of their schoolmates learn that they have a brother or sister who is disabled, siblings may acquire what Goffman (1963) has called a "courtesy stigma." They may be treated as if they, too, are different, especially if both children attend the same school. Parents who are themselves high achievers and who have high expectations for their children may have to significantly modify their goals for their handicapped child.

The School Years: Adolescence

All families experience the series of adjustments parents and children must make as children leave childhood and enter adulthood. As children grow and become more capable, parents must continue the letting go process and begin to appreciate their child's growth, separateness, and independence. For the handicapped child, the body may mature while the the mental, emotional, and social state of the child may lag behind. For parents, this time may be difficult as they realize their child's long term and more acute dependency.

Adolescence is a time when peers have a major influence on one another, and hours are spent in the company of one's agemates. Peer acceptance is extremely important, as one's self acceptance is shaped by how peers, as well as how parents, respond. The visible handicaps can have an important effect on peer acceptance. Other factors that may influence peer acceptance are peers' previous experience with persons with similar handicaps, and their knowledge or perceptions of the impact of the impairment on the individual. First-hand experience with a handicapped child is a major factor in nonhandicapped children's positive responses to the handicapped child. Peer and group acceptance is important in this critical stage for learning appropriate social skills, which in turn will influence societal acceptance in the years to come. As parents observe their child during this period, their anxiety about the future may increase if their child is isolated and spends more time with the family than with friends.

The Completion of Public Education: Adulthood

Public education services, often taken for granted, provide extremely valuable benefits for the family of the handicapped child. The system helps the child acquire independence and life skills. It also offers respite for the parents during the years when their handicapped child receives services for 5 to 6 hours a day. As the end of the child's public education experience approaches, families face the crisis of the future. In Chapter ___, Vadasy and Fewell describe the anxieties and concerns reported by mothers of deaf-blind children as their children neared the end of eligibility for the services they had been receiving since shortly after birth. It is a time for facing hard questions and making difficult decisions, and it is usually stressful. In some areas, and for some children, the choices may be extremely limited. The child may be unable to participate in the decision making process, again reminding parents that they must continue to play a major role in the life of their child with special needs.

The Aging Family

When a handicapped child becomes an adult, decisions must be made as to where the person will live, and the level of care he or she will need. These decisions will often determine how the child will spend his or her adult life, and changes will be relatively few during the ensuing years. The parents may continue to make decisions for their child, or to support the child although the child may not live with them. When the parents can no longer perform these roles, another crisis occurs: they seek ways to make sure their child is cared for when they have died. The advice and assistance of social workers and other family members are extremely important in enabling parents to finally turn over all responsibility for the child to others. This culminating crisis, when it is resolved effectively, can result in the parents' feeling of satisfaction and joy, feelings similiar to those they experience when their other children marry or become independent.

Although family structure changes, families continue to be the major support units in the lives of human beings. Older members nuture younger members, and as the young mature, the process reverses. Outside of immediate family units are a host of significant others who also support families. When a family has a handicapped child, all the actors in this support network must adapt to the extended needs of the handicapped member. The adaptations family members make are often significant, and individual destinies may be determined by the experience. Family adaptations change as the child matures; the stress at various periods may affect family members differently, as much depends on the contributions all family members and the environment make to the dynamic interactions of adaptation at a given point in time.

IMPACT OF THE CHILD ON THE FAMILY

A child with special needs imposes demands which stress the family's ability to function effectively. The entire family becomes more vulnerable to the influences, arrangements and transactions of the environment. The child with special needs can no longer be viewed or served in isolation; the myriad persons, agencies, and institutions that touch the child must be included in a service plan. Hobbs (1980) described the unit of service as "not the child but the child-in-setting," then referred to the system of service as "...ecological to take into account the situational, developmental, the transactional character of the demands on a service delivery system" (p. 275). To be proactive participants in the ecosystem of a child with special needs requires an understanding of the very complex and dynamic interactions within the system that influence one another. Before describing the variables that are within a family's structure, it is wise to be cognizant of McEwan's (1975) appreciation of family differences, and Speer's (1970) reminder of the capacity of our knowledge. David (1979) summarized McEwan's concerns:

> ...each family has its own dynamics of formation, growth, maturation, and dissolution, affected by numerous biological, psychological, sociocultural,

> economic, and educational variables...not all families have functions in every area and...not all areas appertain to each family for the whole of its natural history (p. 305).

Speer addresses our very limited knowledge of what constitutes healthy family functioning, a warning also warranted by the professional tendency to focus almost entirely on family dysfunction, when in truth, many families with handicapped children cope effectively, and some consider themselves fortunate in their experience. Speer asserts: "We know almost nothing about the satisfaction, closeness, meaning-achieving, autonomy, problem-solving, communication, change, and basic relationship-organizing processes of exceptionally well-functioning, broadly and deeply satisfied, fulfilled families" (p. 273-274). These admonitions, should encourage us to view families in the context of their immediate ecosystem, to appreciate the role of each person's history, and to anticipate the impact that present interactions among family members will have on the future well-being of all.

Described in the sections that follow are family variables that are influenced by a child with special needs. In the remaining chapters of Part I, authors convey, in some detail, the impact of the handicapped child on immediate and extended family members, the persons included in what Bronfenbrenner (1977; 1979) has described as the child's "microsystem." Authors in the second part of this book address the impact and service transactions of persons, agencies, and institutions within what Bronfenbrenner views as the three remaining levels for analysis of human development, the "mesosystem," the "exosystem," and the "macrosystem." These enmeshed systems are comprised in the complex ecosystem that must be considered to plan successful interventions.

Interactions Between Parents and Children

Before describing family interactions that are influenced by one member's disability, an understanding of what constitutes a family is needed. In the context of this book, a family refers to those persons who provide for the handicapped child's biological needs and nurture the child's development toward becoming a person, capable of participating in society to the fullest extent possible.

The interactions between a parent and a child are always unique. Each child's birth is anticipated and dreamed about. The bond between parent and child that begins before birth strengthens after birth as the dyad members come to know one another in new ways. Klaus and Kennell (1978) describe the early engaging interactions between parent and child, during which behaviors such as fondling, kissing, cuddling, and prolonged gazing signal an emerging attachment. The birth of an infant with impairments has an immediate effect on these early interactions. The family's dreams and expectations are threatened by the initial diagnosis. The information is shocking and is never forgotten. Feelings of intense emotional upset are described by parents (Allen and Allen, 1979; Featherstone, 1980; Murphy, 1981; Turnbull and Turnbull, 1978). With time, equilibrium returns, and the parent and child begin to know one another.

All infants contribute to their own development. The parent, in responding to the infant, is changed by the infant, and reciprocally, the infant responds to the parent and is changed by the parent. Infants with impaired systems have a more difficult time communicating their needs, feelings, and states. This communication process can be frustrating for parents and can result in inappropriate responses to the child. Learning to communicate effectively with the handicapped child will take longer. Parent and child may develop a private system of communication that is not readily understood by others but that meets their own special needs.

Impact on Siblings

Each member of the family will have to make special adjustments to the handicapped child's special needs. Grossman (1972) conducted the most extensive study of siblings, studying 83 college students who had a retarded brother or sister, and a matched control sample with normal brothers and sisters. Grossman's data revealed the following findings: 1) A number of subjects benefitted from the experience, in that they seemed to be more tolerant, more goal oriented; 2) some subjects were bitter and felt guilty about their feelings toward their parents, and many feared that they too would be defective; 3) parental attitudes and reactions to the retarded brother or sister were the strongest single influence on the normal sibling's acceptance; 4) siblings from upper-income families experienced fewer burdens than siblings from lower-income families as their families did not require as much help from them in the caregiving role. Graliker, Fishler, and Koch (1962) reported very positive effects after interviewing adolescents ages 13-18. Breslau, Weitzman, and Messenger (1981) also reported positive reactions, although their findings were mixed; they found that older female siblings may be more at risk than younger siblings. Featherstone (1980) reports many examples of mixed reactions. Clearly, many factors interact to determine siblings' reactions, with their responsibilities for the child being a pervasive element in their immediate and long-term reactions. For more information on sibling interactions and reactions to handicapped brothers and sisters, see Chapter __ of this volume.

Impact on Grandparents and Kin

It is often not appreciated how strongly the birth of a handicapped child affects grandparents and other family relatives. Grandparents often experience a dual grief--a mourning for the loss of an expected grandchild who would carry on the family tradition, and a sorrow for the lifelong burden and reduced opportunities their own child faces in raising the grandchild. Fortunately, professionals are beginning to realize that grandparents are a potential source of support for families. Gabel and Kotsch (1981) describe a program designed to help grandparents and other extended family members express their support in productive ways. In their studies of family supports, German and Maisto (1982) and Vadasy and Fewell (Chapter __) both found that grandparents were very important sources of support for parents.

The support of an aunt, uncle, or another relative can also be extremely important to the handicapped child and the parents (Schell, 1981). When these relatives don't seem to understand or enter into a supportive role, their reactions to the child can be extremely painful for parents (Ferris, 1980).

Members of the extended family, although at greater remove from the child, are also affected. Kinship bonds transcend space and generations, and these relationships can be the source of important social support for child rearing tasks; when these family members do not respond for one reason or another, there is a void and the family's tasks are more difficult.

Family Roles

Individuals fill a variety of roles, both inside and outside the family, and these roles vary across time and conditions. Shakespeare described it thus:

> All the world's a stage,
> And all the men and women merely players:
> They have their exits and their entrances;
> And one man in his time plays many parts,
> His acts being seven ages. (Shakespeare, As You Like It,
> II, 7)

In an interview with a father in the SEFAM Project at the University of Washington, a father was asked the following question which explores the issue of role changes for a parent of a handicapped child:

> Interviewer: When you come to the class, you have to assume a lot of the caretaking jobs that traditionally have been left to the mother, such as feeding and changing diapers. Did you change a lot of diapers with your (nonhandicapped) older daughter?
>
> Father: No way. I think it's more the mom's role, but it shouldn't be, it's just the way society thinks. But when you have a handicapped child, it can change your whole outlook on life. It's like someone dropped a curtain in front of you--you gotta change. If you had a normal kid, things would have been tromping along, mom would have continued changing the diapers. When you have a handicapped kid, you gotta start thinking about new ways to do things--that means changing diapers and stuff.

This father's reaction was instant and to the point, a clear indicator that family members will need to provide more support for one another and, indeed, take on roles that they had not anticipated. Often, the new roles are added to the traditional roles which family members are expected to continue as they maintain their self-esteem, their integrity as a family, and their place in the community (Turnbull and Turnbull, 1978).

Vadasy et al. (1984) investigated the roles of mothers and fathers of 23 young handicapped children in the SEFAM program and found evidence of the demands experienced by the parents, particularly the mothers. The majority of the mothers (65 percent) reported they spent over 5 hours daily with their special needs child, while only 27 percent of mothers said they spent over 5 hours daily with the other children in the family. While there was disagreement between parents as to who was responsible for most of the child care, 61 percent of the fathers and 57 percent of the mothers agreed that the mothers were responsible for most of the child care. Thirty-five percent of the fathers, but only 4 percent of the mothers felt child care was shared equally. When these parents were queried about housework, 39 percent of the fathers, but only 13 percent of the mothers said the housework was shared equally.

Gallagher, Cross, and Scharfman (1981) also investigated parent role responsibilities in families with a young handicapped child. The researchers compared responses from mothers and fathers on the Gallagher-Cross Parent Role Scale. For each of the scale's 20 role dimensions, parents indicate who plays the role in their family by scoring items along a 5-point continuum, ranging from "father alone" to "mother alone." The researchers found remarkable agreement between mothers and fathers as to who performs what roles. The data provide a portrait of traditional family role responsibilities, with the six roles directly related to child care being carried out predominantly by the mother. Further analysis revealed fathers felt they should participate more in family activities involving the handicapped child, and the mothers' responses concurred.

Role demands, particularly those experienced by mothers, were poignantly conveyed by a mother interviewed by Winton and Turnbull (1981). Commenting on her desire for a break from the responsibilities of child care during school hours, she said: "A lot of times I get tired of having a role--God, I don't want to solve that--I am paying you to take him for 3 hours and lady make it work" (p. 15).

Farber and Lewis (1975) are particularly sensitive to the tendency of educators to lose sight of the role of the parent as family member, and to regard the parent as a teacher, failing to appreciate, in their opinion, what is unique about parents' roles: "The parents are then symbolically rather than functionally used." The authors provide an excellent example, so common in many programs: "The parent may be required to imitate the classroom teacher in his or her orientation to the child..." or "...act as a parapro- fessional..." (p. 40). Parents who are used in such a manner are not permitted to fulfill their primary and unique roles: "The parent role has meaning only as a component in a complex of family roles. In effect, by undermining the special qualities of the parent-child relationship, which is a highly personal experience involving parents and sometimes grandparents, as well as siblings as significant persons, these programs turn the parents into just another group of school personnel, another group of adults trying to be helpful" (p. 40).

As we noted earlier, siblings can also be asked to take on more of a careproviding role than they would have ordinarily. Older sisters appear most likely to be asked to assume a greater role in caretaking, a finding in studies by Farber (1959) and Grossman (1972), and discussed by Seligman (1983). For many, these extra roles have had a direct and positive influence on their futures, as in the case of this sister of a severely handicapped sibling: "The choice of a career then became obvious to me. What better way was there to serve others than to enter the field of special education where I could help people like my brother lead more fulfilling lives" (Helsels, 1978 p. 112). For some, the added responsibilities mean that the sibling must sacrifice other social, athletic, or school activity in which the sibling would otherwise participate.

Family Time

The time demanded to provide help, support, and care for a child with severe impairments can amount to an intensive, exhausting, never ending 24-hour care routine (Lyon and Preis, 1983). Parents may feel they must give all their time to their handicapped child, and may fail to take time for themselves. Klein (1977) reported that several sets of parents of deaf-blind children said they had never been on a vacation alone, and seldom went out on weekends because of the difficulty in finding a babysitter.

While many of the time demands originate with the child (e.g., the extra time it can take to help the child eat, drink, toilet; travel time to school and community services), community agencies can also demand a parent's time. Parents who have the responsibility for 24-hour care of a child with special needs sometimes need a break; they may not want to have to work in the child's classroom once a week, or more often in some cases. Parents may not feel comfortable admitting these feelings, particularly when they are first searching for services. At this time, the parent is particularly vulnerable, and often feels unprepared for the task of parenting the child. Parents often feel great relief and gratitude when they first locate services or a program for their child. Contrary to what they might have expected, once the parents locate professionals who apparently have the skills to help the child, the parents may find that the agency professionals also want some of the parents' time. Caught between their child's needs and their own desire and need for relief and respite, the parents often succumb to the professional's demands for fear of being perceived as "bad" parents if they are not willing to give the extra time to the class. The demands that parent participation programs often make of parents are viewed by Farber and Lewis (1975) as "representative of the kind of innovation which is characteristic of the enterprise model of educational organization and function," and Horejsi (1979) has commented on the higher social and psychological price that parents of handicapped children must pay for 6 hours of relief during the school day. The benefits of parent participation are often more clear to professionals than to parents. The practice is cost-effective, and if the children do not show the heralded benefits, "the managers have a built-in scapegoat for explaining failure--the inability or low motivation of parents to act as teachers or tutors to their own children" (p. 39). Thus the parents who go along with an agency's demands against their own instincts, and who fail to ask what alternatives are available may find themselves both used and abused in far-reaching ways. While parents' experiences will vary (e.g., Jablow, 1982), it behooves agency personnel to be sensitive to parents and their needs at a given point in time; circumstances will change, and needs will also. Maybe later a parent will want to be in the classroom almost daily, but perhaps not for now.

Family Finances

Responding to a child's special needs will be costly. Added expenses are simply a fact of life, be it a relatively minor expense like eye glasses, special shoes, or a hearing aid, or major expenses that will be experienced across a life span, such as special living arrangements, special services, or adaptive equipment for movement in the community. It will cost more for families and for community agencies to provide for individuals with special needs. Community agencies are accustomed to providing special services, and are thus aware of the costs of adding a new person to their rolls. Their budgets are designed to absorb the expenses. Families seldom anticipate these expenses, and they may be overwhelmed by the costs. The financial difficulties of providing for the child's special needs are reported often (Blackard and Barsch, 1982; Christ-Sullivan, 1976; Dunlap and Hollinsworth, 1977; Moroney, 1981). Yet families manage to find ways to continue the caring function. Moroney reminds us that "large numbers of handicapped children are living with and being cared for by their relatives--far more than are in institutions" (p. 194). Yet, Moroney continues, "we have not developed a network of supportive services for these families" (p. 194). He (Moroney, 1979) has pointed out that our knowledge of how to substitute and take over for families is much more developed than our knowledge of how to support families as primary caregivers. He suggests that professionals view families as needing resources to carry out their responsibilities rather than viewing family members primarily as resources themselves.

Family Relations with Society

Throughout this book, the overriding concern of authors is to faciliate understanding and support for families of children with special needs. In their chapters, the authors share their insights and the insights of others, and they suggest strategies to help families respond to exceptional needs. It is one thing to work with the persons within a handicapped child's immediate and extended family to plan and provide services and respond to needs; it is more difficult to identify and to rally support for these human needs from society at large. It isn't that "society" doesn't care. The issue is far more complex. It involves social policy for the handicapped, underlying attitudes about the role of the handicapped in society, and assumptions about family responsibility. Families with special needs face a number of obstacles in their efforts to help their handicapped members fit into society and to obtain needed resources. Family and social values are discussed briefly in this section.

Many attitudes towards handicapped persons are derived from historical references that assign handicapped persons to the roles of beggars, freaks who were placed on public display, or court jesters whose uncontrollable movements were regarded as entertainment for others. Always, handicapped persons were considered liabilities to their families and society (Lowenfeld, 1981). Even the word "handicapped," derived from "cap in hand," conveys a negative image.

More recently, society has come to define an impairment as a medical condition to be "treated." Society provided what became known to many as "state hospitals" or places where persons with mental and/or emotional problems were supposedly "treated," but were more often "warehoused" for the remainder of their lives. Recalcitrant children were often threatened with banishment to such places, or of causing their parents to succumb to dreadful destinies such as their death. The stigma of the handicapped person is one of shame and inferiority (Wright, 1960), which marks the person as tainted and discounted (Goffman, 1963). Such views are not consistent with normal societal roles of friend, lover, co-worker, or autonomous adult (Gliedman and Roth, 1980), and society is reluctant to change its views. While attitudes have changed and the handicapped are no longer ostracized or warehoused, the current use of the medical model in planning services often means that we lose sight of the person behind the handicap. For many handicapped individuals and their families, the most devastating consequences of being handicapped are often not the direct physical or mental results of impairment itself, but rather the attitudes and reactions of those who are not handicapped. Georgie Miller (1981) conveys convincingly her feelings about society's attitude:

> I detest the thought of anyone saying, She's blind. It makes me madder than anything, because I am not blind. I'm visually impaired, or visually handicapped...A lot of people automatically start treating me like a piece of china, and I detest that. I am a person, and I don't need to be handled like I'm going to break. I've always felt that way (p. 152).

The value society places on persons with impairments is also reflected in whether persons with impairments are given entry to everyday roles and activities, or are kept at a distance. This tendency to distance ourselves from the handicapped is illustrated in our answers to questions such as Would you rather be deaf, or blind, etc. The less obvious an impairment, the more socially acceptable it is. Moderately handicapped persons can often fit into both the nondisabled world, and the world of the handicapped. Yet, the ambiguity of moderate conditions is itself a paradox: it permits one to participate in society at certain times and under some conditions; at other times and under different conditions, the person is clearly excluded. So that, while the label may be a useful tool to obtain services, it may also be a stigma that will do far greater damage to the person's self concept.

Finally, another problem with relying upon a diagnostic label to provide services for the handicapped person is that it fails to consider services the family needs to function. Fortunately, professionals are beginning to recognize the irony of this situation in light of social policies which stress deinstitutionalization and community placement. If families are to provide care, they must be supported in their efforts.

The family's role is made easier when members receive appropriate economic supports and services, as well as emotional and social support for their efforts. These latter intangible supports, which provide important psychological benefits to families, depend upon social attitudes towards the handicapped. Martha Jablow (1982), a mother of a handicapped daughter, understands why persons "squirm, fidgit and change the subject" (p. 172) when retardation is mentioned. She pinpoints the fear that prevents many from seeing the person behind the handicap. In her enlightening and moving book, Cara, she also expresses hope for change with future generations:

> I understand this discomfort. I have felt it myself. While waiting for a train, I was approached by a young man who sat down next to me and began a conversation about his friend who worked in a pet store. The young man was clearly retarded, his speech understandable but repetitious. I would just as soon have been somewhere else. But I thought of Cara and hoped that a stranger at a train station would be a patient, cordial listener if she initiated a chat. I recognized in my first reaction to this young man the unease that causes many people to fear the retarded. And I wondered how much of that fear is at the root of many people's reticence to integrate the retarded into their communities and schools. Until future generations become more accepting of their brothers and sisters with handicaps, uneasiness about the subject will continue (p. 172).

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"THEY BECAME A SUBSTITUTE FAMILY": THE EFFECT OF PROFESSIONALS ON THE FAMILY OF A HANDICAPPED CHILD

CATHLEEN TOOLEY MOELLER

IN: FAMILIES OF HANDICAPPED CHILDREN:
NEEDS AND SUPPORTS ACROSS THE LIFESPAN

Prepublication Draft

"They Became a Substitute Family": The Effect of Professionals on the Family of a Handicapped Child

Kathleen Tooley Moeller

OUR FAMILY'S INITIAL EXPERIENCES

I am a parent. Anyone who has ever approached parenthood knows well the anticipation and small fears that cross your mind as you await the birth of your child. I fully expected that my third child would be born beautiful and healthy, and would have just as brilliant a future as our first two sons. The very worst I ever expected from my third pregnancy was the disappointment that I would have another son rather than the daughter we dreamed of having.

Our child was born beautiful and healthy, with ten fingers and ten toes. Nothing was missing, including the magic that displaced whatever disappointment I had that he was another boy. I was soon shocked, however to learn that our seemingly normal, healthy, beautiful child, because of an extra chromosome, number 21, was also a statistic--one child out of 750 who is born with Down syndrome. Our precious baby had not been in this world but 5 hours when this shattering news was delivered by a genetic specialist, a person who to this day I would not recognize if she stood face to face with me. When I received the news, I secretly prayed that the genetic specialist would be a victim of human error. Even when she announced the diagnosis, I insisted that she explain to me just how SURE she was. She explained that based on her expertise, she was 98 percent certain of her initial diagnosis. I clung desperately to that small 2 percent of uncertainty, but somehow in my heart felt a loss, because I knew she was right. The joy we felt briefly as new parents was stolen away by a person who never even bothered to introduce herself to us by name. My life, my husband's life, our marriage, and the lives of our children would never be the same again. From the moment we received the diagnosis, we would never be a "normal" family.

Once we received the chromosome test results that confirmed our little Matthew did have Down syndrome, trisomy 21, there was no longer a shred of hope that the doctors could possibly be mistaken. Our instincts then drew us together as a family. Strange doctors, including the nameless genetic specialists, outsiders to our family, had just given us the most brutal news possible, wounding our family in the most intimate way. To us, their clinical language and impersonal talk of statistics were weapons that threatened an innocent baby--more importantly, our precious baby! We huddled together to protect ourselves against the intense pain and grief we were experiencing.

It's difficult to give a time or date when the hurting stopped, but in its place came an enormous strength. The pain reminds me of a chronic bad back. You never know when it's going to flare up and suprise you, and remind you how vulnerable you still are. I believe inside all parents there resides a strength that is borne out of love for their child. The more we got to know our son and become knowledgeable on his disability, the more the pain eased. When we fell in love with him, we came to the realization that no matter what, we would survive, and then the pain all but disappeared. The grief we felt for the loss of the perfect baby we wanted diminished as we realized that Matthew was our real child and we ceased to compare him to the imaginary child we thought would be born to us. The pain returns occasionally, but once parents come to terms with their child's disability, they take the first step in the process of putting their lives back in their own control. Each time the pain brings on the familiar feelings of sadness, fear, and doubt, we as parents draw on our most potent reserves, the love we feel for our child.

Our next step in protecting ourselves from further pain was to become informed on our child's disability. This information not only protected us from the fear and confusion we experienced in our encounters with medical professionals, but it also made us feel a sense of control. We read everything possible on the subject. We prepared ourselves with information on the very best we could expect for our son's life, and the very worst. As we broke the news to friends and family, we felt we had sufficient information to answer any and all of their questions.

In the time just after we received the diagnosis, we tried to use special family members and very close friends as a support system to alleviate our painful grieving. We expected that our pain would diminish as we shared our grief with loved ones--that their strength and love would ease our burden. We were, however, frustrated when this sharing did not ease the pain. In fact, the more we talked to family and friends who were close to us, the more we tended to take on their shock, pain, and upset at our situation. We were, as we soon discovered. creating a vicious circle of grief! Their pain added to our pain, and as a result, our entire family floudered emotionally. We needed to step outside this vicious circle we had unknowingly created and draw some strength and guidance from others who were not caught up in the emotional experience of Matthew's birth.

It was difficult and discouraging to come to the conclusion that we could not find the freedom from our intense emotional pain from the people we loved and trusted most, including each other. We knew we needed support from others who had been where we were now, groping for bits and pieces of information that somehow enabled them to survive.

The Professional and Parent Support Networks

At this point we were fortunate to be put in contact with a variety of professionals who, as it turned out, would influence every aspect of our child's life as well as our own reactions and ability to help Matthew. As these experts slowly entered his life and the lives of everyone in the family, we began to absorb their hope, their honesty, and their encouragement, and to regain our strength as a family.

The doctors with whom we had been in contact when Matthew was still in the hospital led us to believe that we should feel lucky that people with Down syndrome now have lifespans that are almost as long as normal, and that they are no longer being institutionalized. "Lucky" was not how our family felt, however, during those first few days in the hospital. We were soon fortunate to meet a very kind nurse from the hospital who referred us to a parent-to-parent support group. The family coordinator and head of the group, Ann, called me, and before long, seemingly worked miracles. She had a grown child with Down syndrome who was actually living on her own! This wonderful woman gave me tangible information, and I clung to her every word. Ann helped me understand our child's disability in ways books could never relate. I learned that my child could learn almost anything if someone took the time and patience to teach him. He would be able to attend regular schools, like my other two children, and get appropriate school services in a special education program. I glanced down at my tiny sleeping baby knowing he too would one day wave goodbye to me, lunchpail in hand, while climbing on board a big yellow schoolbus. That knowledge somehow seemed so important to me that I cried tears of sheer relief. This other mother had convinced me that our family could look forward to living a full, happy life with our handicapped child. I listened eagerly as Ann went on to tell me that her daughter even kept track of her own checking account, and Ann said she knew of a few adults with Down syndrome who actually had their drivers licenses! I have a terrible time with my checking account, and had just recently had to retake my driver's test. Ann gave me hope and the strength to face the world. We shared a certain common bond, because she knew without a doubt exactly the feelings I was experiencing. I was one of over a hundred mothers with a disabled child that she had counseled, but because of her understanding, my family and I will always have a special place for her in our hearts. She helped us to feel hope, and although we realized it was just the beginning, we saw that we would be able to survive.

Ann also put my husband in touch with the leader of a wonderful program designed just for fathers and their handicapped children. The man to whom my husband spoke was a teacher of handicapped toddlers, and also the parent of a preschooler with Down syndrome. Through this program my husband also began to feel the first of many feelings of solace. This fathers program offered a series of informative lectures dealing with every aspect of our child's life, from infancy to adulthood. The lectures provided information on medical and legal issues, and sibling and family problems. The fathers learned how to offer emotional sustenance to the immediate family, as well as to help extended family members adjust to the handicapped child. My husband speaks very highly of the two men who run the program, and feels a certain unspoken intimacy and sense of gratitude towards these men, whom he feels put him back in touch with reality.

> I feel a lot more relaxed about the love I feel for my son. I realize now that the whole family does not have to sacrifice their lives for the sake of the handicapped child. Having a father who has a handicapped child head the fathers program definitely gives the program credibility. He knows how I feel.

Our Child's Infant Program

When Matthew was an infant, we enrolled him in an early intervention program in a university setting where he was seen by a special education teacher, as well as a physical therapist. This marked the beginning of our relationship with a great many professionals who would enter our lives through their involvement with our son.

When I placed Matthew into a strange woman's arms on his first day in the infant program, I was quite unsure of what she hoped to accomplish with my 4-week-old baby. I watched her as she checked his reflexes and conferred with the therapist. She cooed softly to him, and smiled proudly when he accomplished certain tasks, such as following an object with his eyes. I had no idea that first day of what their expectations were for Matthew and myself; all I knew was that I began to feel safe in their presence. I trusted them, and I sensed from the start that instead of the negative and critical tone of our conversations with doctors, their observations and comments seemed tc have a more positive note. In those first few weeks, I was mesmerized as I watched the teacher and the therapist. They would hug my baby and praise him with sweet baby talk after a "workout." As the weeks and months passed, I sensed my baby's growing attachment to his teacher, and his response to her obvious delight whenever he accomplished a new feat. I, too, unconsciously formed my own attachment to her. I began to share with her small anecdotes about his cute or funny behaviors at home, my feelings about his handicap, problems with his brothers' reactions to a new baby -- even confiding to her the new-found closeness I was experiencing in our marriage since Matthew's birth.

I soon found myself looking forward to the sessions with the teacher and physical therapist. I felt I finally found a place where my child and I could really feel safe. Other mothers to whom I spoke shared the same feelings, and as one mother put it:

> I found myself feeling proud of my child. Her teacher was so thrilled to hear of everything she did at home, and was almost as delighted to learn of her first sitting up as we were! We called and told her before we even told the grandparents, we felt she had a right to be one of the first to know.

These sessions were a place where my child was not judged on what he could not do, but rather on what he could and would eventually be able to do. It was clear that we were all working together to make him the very best person he could possibly be. When I later asked the infant teacher how she was able to make new parents, who were often quite devastated and still in shock, feel so positive about their child, she replied:

> In the very beginning, I realized that I am that baby's first teacher, and the parents are still in a great deal of pain. So I keep stressing positive statements about the baby, as a way of comforting the parents. Every baby has potential, and it is important for parents to know that right away.

Professionals who work with families in the early months of the child's life can have a profound influence on parents. A mother may hear the first hopeful words about her child from the teacher or therapist. And those words and assurances can become the basis of strong attachments, acknowledged or unrealized, between parents and program staff.

PARENT AND PROFESSIONAL ROLES AND RELATIONS

The First Parent-Professional Relationship

The school terms went by, and my child was soon assigned to a new teacher and a new therapist. I guess I was emotionally unprepared for this change, because I felt devastated and bitter that these people who had spent so much time with our baby, as well as with us, could desert us. I definitely felt an emotional void in my life, and I could see Matthew was confused as to the whereabouts of his old friends. It was difficult to remember that these people did not drop out of the heavens into our lives only, but rather were trained to do a certain job. When they had finished their work, they would refer my child to the next set of professionals who would meet his changing needs. It was equally hard to keep in mind that these people worked not only with my child, but with a dozen or so babies a week. I had a conversation with one mother and I was relieved to hear her say out loud the same feelings I had secretly harbored.

> I had to change my daughter's therapy session because she had been sick, so I ended up coming on a different day than usual. I walked in the room and was so taken aback to see her (teacher) with another infant, holding and talking to him just as she did my child!! I was crushed. I thought we were her favorites -- I was actually jealous.

Every mother I interviewed, when asked, expressed the same feeling. We all had attached ourselves so steadfastly to these first teachers and therapists that it was difficult to realize they could have similiar feelings for all the babies they saw. As one of the mothers interviewed by Winton and Turnbull (1981) has described, they became a substitute family for us, and we felt as possessive about their relationships with our individual children as we would feel if an aunt or uncle took on a strange child and showed the same love and affection they had shown for their nieces and nephews. My son's first teacher, who understood the importance of the child's first teacher in the parents' lives, has made a few ground rules for her student teachers to protect everyone's feelings.

> I insist student teachers work in the classroom for at least two quarters, because the transition for parents, to have teachers switched more often, is just too difficult for them emotionally.

This emotional attachment is also a two-way street: teachers and therapists also become emotionally involved with the children, and sometimes much more than they anticipate.

> I used to worry late into the night about a particular baby I was working with, or a family that I felt wasn't coping well. I'd become preoccupied with the emotional well-being of everyone concerned with that baby. I soon found that I didn't have a life outside of my job. I had to draw the line in order to survive as a person. It was a painful learning experience, not something they taught us in school.

I have tried to reflect back to the time of my son's infant program, and reconstruct how this attachment between parent and teacher formed. I remember my first year in the early intervention program. While the teacher would be working with my child, I would talk to her and ramble on and on about one thing or another concerning my son's disability, mostly about how we, as a family, were or were not adjusting. I remember that she used to glance up at me occasionally and nod her head to let me know she was listening, but rarely, if ever, did she reply. She told me much later that she felt that if she reponded to my personal concerns, she would have jeopardized the quality of our parent-teacher relationship, causing it to become an emotionally dependent one, and further, one that she did not feel she was trained or prepared to handle. Looking back on the situation now, I remember that I felt grateful she was such a good listener, and I simply thought that she was just a very quiet person. I now know why she was so quiet.

The Quality of the Parent-Professional Relationship

I have spoken to a variety of families of handicapped children, all of whom have known professionals who have played an important part in their lives and the life of their child. These people include doctors, teachers, physical therapists, speech therapists, occupational therapists, communication disorders specialists, nurses, lawyers, and administrators of the programs that eventually mainstream our children into the world. The families spoke of these people with varying degrees of like and dislike: their judgments, however, seemed to be based on the professionals' emotional response to their handicapped child.

> I felt she (the teacher) was a very knowledgeable and highly trained individual as far as her profession went, but we made the decision to change teachers because we didn't feel she was sensitive to our child. She should have held him and talked to him more lovingly -- after all he's just a baby. He often cried after she worked with him. I thought her manner with him was rather brusque.

The quality of the parent-professional relationship is one of crucial importance. Parents have need for technical information, for skill training, for counseling and support services so that the handicapped child, as well as the family, can live as normal a lifestyle as possible. This learning process is one that cannot be accomplished solely by reading books (what parenting skills can?), nor can books provide the confidence parents need to feel comfortable making important decisions for their child. This is where professionals can help the family by sharing their knowledge and experience.

The professionals who are in constant touch with the handicapped child must develop a rapport with parents that is based on trust and genuine caring. Guilt is, unfortunately, a burden almost all parents carry around with them in one form or another, and parents of handicapped children are even more likely to experience it. We ask ourselves: "Am I doing enough?" "Should I spend more time with him?" "Am I expecting too much?" and of course, "Are my expectations too low?" We feel at times that we are too preoccupied with our handicapped child, and then turn around and feel that we were not worried enough! It's a difficult job being a parent, especially one with a child with special needs.

When we get together in parent meetings, or when some of the parents are observing their children at school, we all go through the feelings that I've just described. At those times, the parents who are feeling particularly up seem to be of great help to those that are down. The group exhibits sort of a see-saw syndrome! We did discover, however, that the message we were always passing to one another was to take care of ourselves, learn to be a little selfish, and cherish our spouses, to make time for the things we want to do instead of the things we feel we have to do. We never absorb the advice all at once, but keep passing it around to whoever needs it the most. A couple who were more guilt-ridden than most of us experienced the most positive effects of our group's encouragements.

> We went on vacation and after a lot of agonizing, left the girls with my parents. In that one week alone with my husband, we shed all the negative feelings we'd been harboring, and realized life was to be enjoyed! Our handicapped child was doing the very best possible. We realized that as parents that was the ultimate goal we could hope for -- in any of our children! We finally quit looking at life so seriously. It was a wonderful burden to shrug off!!

Professionals who are sensitive to these parental feelings can offer the parents guidelines to help them evaluate their level of involvement with their child. When parents reflect upon their experiences with professionals, the first thought that often comes to mind is the quality of their relationship with the professional, and their feeling of being respected. The sensitive professional respects the dignity and integrity of the parent's role, and regards the parent's input about the child as unique, useful, and worthy of respect.

When the relationship between parent and professional flourishes, it is one of the most rewarding and satisfying relationships a parent could have. One family I interviewed is so devoted to their child's physical therapist that she is often a dinner guest in their home. Their opinion of her is strongly influenced by the therapist's attachment to their child.

> I like her very much. I felt that in the first months she was undergoing some transitions in her personal life, and she often seemed disorganized and confused. But as soon as she held my baby, she was able to get her to do anything! I feel she was as attached to my baby as an aunt would be...I knew she cared deeply, and I just felt confident that she would eventually get her act together.

Parent and Professional Expertise

Next to the parent, the teacher is probably the most important person in a child's life. The parents view the teacher as the "expert," looking to the teacher for direction, information, and assurance. The relationship is one of heartfelt intensity. The teacher must maintain an open, honest relationship with both parent and child. The teacher's impact and responsibility is indeed profound, but teachers should also keep in mind that they have much to learn from the parents. The parent is the best asset a teacher could have in understanding and helping a handicapped child, and unfortunately the least used.

> I argued with the teacher until I was so frustrated I wanted to cry. My son was being placed in a program with other children who were academically too advanced for him. I couldn't make this teacher understand how far my son had come emotionally and mentally since the previous year. He is supposed to be a special education teacher, but he argued state funding with me while I was just trying to tell him that Timmy needed more time before he was ready for this program.

Professionals tend to take on an authoritative role in the life of the family with a handicapped child. It is only natural that we parents view professionals as experts, and naturally we assume they know what programs are best for our child. The parents tend to feel somewhat helpless and in awe of the professionals they come in contact with, especially during the first early years. The parent is often reluctant to argue or disagree with the professionals, fearing that the child's program or special services might be jeopardized. This of course is not the case, and parents need to understand this. Professionals also need to keep in mind that parents are most understanding of their child's needs, and to let parents know they value thei unique insights. As one mother of a blind child has described her feeling about her son's nursery-school teacher who acknowledged the parents contributions:

> They restored our parental expertise by consulting us about how we handled specific situations in the home that were problems in the classroom. They made a point of telling us when we were doing something right...We were finally given the chance to pull together as a family, to begin to heal (Stotland, 1984, p.73).

One of the professional's most important responsibilities is to provide direction. There may be a difference of opinion as to the services required for the child. The services that are available to the parent may not all be equally effective or successful. Parents are often referred to various sources for answers, and they must determine how to best select the services that are available to them. While parents have their individual means of adjusting to life with a handicapped child, they all have one thing in common: they share this struggle of trying to find the most appropriate services for their special needs child. Parents who have experienced a lack of response to their child's needs will be overwhelmingly grateful to a helpful professional. Parents' vulnerability to inadequate information and supports is reduced by the formation of parent advocacy groups, and increased public awareness of their needs; however, the struggle for parents is hardly over. Persons in the legal, medical, and educational professions must remember their influence on the lives of parents of handicapped children and do whatever they can to support parents in their unique role.

Keeping Parent Needs in Mind

The parents of a handicapped child experience many of the same feelings as parents of "normal" children, while at the same time they cope with the overwhelming parenting demands imposed on them by a child who has special needs. A handicapped child needs more time, more energy, more patience, and more money than a normal child. Often these parents give more of themselves, and get less for their parent egos in return. It is vital that teachers and therapists keep this in mind when prescribing exercises or extra tasks for the parent to practice at home. One parent expressed her frustrations this way:

> I have three children at home, all preschool age, and my youngest is handicapped. It takes all the physical energy I have to cope. I was supposed to work on his fine motor skills at home for an hour each day between

> therapy sessions. I felt so inadequate that I didn't have the nerve to tell the teacher I couldn't even begin to find the extra time.

Teachers and therapists are sometimes so caught up in their enthusiasm to put a new theory into action that they don't stop and think about the additional demands they are placing on a family that is already struggling to cope. One fairly outspoken mother finally could no longer stand the pressure of having to work with her child so often at home; she felt her life was revolving entirely too much around her handicapped child, while the other family members also needed more of her available time.

> I can't solve all his physical problems! I feel like telling the teacher, "You know the job, you're the expert - you make it work!" I get tired of trying to be so many different people and be good at all of them...wife, mother, special mother, employee. I can't make it all work, and I don't pretend to know how. I feel like a lot should get done in the three hours she (the teacher) has him. I expect her to make my life easier, not harder.

The parents to whom I spoke said that they preferred that their involvement with their child's teacher be informal and give-and-take in nature. They felt that the teacher's role was more properly that of decision maker for their child's educational needs. While the parents felt very strongly that they wanted to have input concerning their child's program and that their information should not be taken lightly, they felt that educators should finally determine the goals, objectives, and methods of instruction for their child. On the other hand, parents preferred to have total control in deciding what types of records should be kept, what medical services should be provided, and when the child should be transferred to another school. For the most part, there is a joint responsibility for decisions affecting the child, with teachers and parents contributing more or less, according to their expertise. There is of course, a question as to whether active and joint decision making on the part of parents and educators is a realistic expectation when applied to all parents.

Keeping the lines of communication open between parents and professionals is of course essential, both for the success of the child's program and the parent-professional partnership. When working with a child, professionals have to keep in mind the expectations parents have for their child. These expectations can help the professional decide upon a program that is best suited to all three involved: parent, professional, and child. I asked parents to share what they thought were the best questions that professionals had asked them, or questions that they wish had been asked, and the following is a result. Questions similar to these were presented to parents prior to an IEP meeting in a study done by Goldstein and Turnbull (1982).

What skills do you think your child should be performing?

Are there problems at home (behavioral, physical, verbal) that can be helped by work at school?

What kinds of a discipline and rewards have you found to be effective?

How does your child best use his social skills at home with friends and neighborhood children?

Does your child have any problems dealing with other peer groups?

What do you feel are your child's strengths and weaknesses?

These kinds of questions encourage parents to share the kind of information teachers do not have access to about the child's home life, and to share insights that parents gain in their unique relationship with their child. Professionals who ask these questions also acknowledge the parents' expertise and help parents become aware of their potential to contribute to their child's school program.

Father-Professional Relations

Fathers, as well as mothers, respond emotionally to the professionals who work with the young child and the family. I had a very enlightening interview with the father of a toddler with Down syndrome who had just recently recovered from open heart surgery. He, too, related the strong feelings he had towards the professionals he had come in contact with in his child's life. His first contact was with his child's pediatrician when he learned of his daughter's disability.

> I felt like an outsider. I remember the doctor came into the room and looked right at my wife and told her that it had been confirmed by the genetic specialist that Paula had Down syndrome. I was devastated. I love my daughter too. The worst part of it was that the doctor only managed to catch my glance as he left the room.

This couple went on to learn that in addition to their child's genetic defect, she also had a life threatening heart problem. They had to make a series of difficult decisions that would affect their child's future, and they decided, against their doctor's advice, that their child should undergo the heart surgery. The father recalls this terribly emotional time for their family:

> When we went into the surgeon's office to discuss Paula's surgery, we had to make a life or death decision based on the information he was about to give us. But in the entire time he talked, he looked directly at my wife. I kept trying to ignore the situation and just listen. But it was just too important. I finally had to stand up and demand that he look at me when he spoke. It was obvious by his surprise that he was totally unaware of his insensitivity.

The father recounted similar experiences when he occasionally accompanied his wife and child to school or therapy sessions. He noticed that when they went down the halls and encountered a professional who worked with the family on a regular basis, the teacher or therapist would always look at his wife first, and only later look at him. I first thought that the father had probably overreacted, and was especially sensitive. I did, however, mention the conversation to my own husband, and asked about his own experiences. He too remarked that he felt a bit awkward about attending a therapy session or just showing up at school.

> Even as his father, I feel more like a visitor than a parent. I guess I've just relied on second-hand information about our child that the professionals give the mother.

One father to whom I spoke has a special needs child of high-school age. He felt that fathers are cast into a back seat role, often beginning with the child's birth. As a result, professionals often overlook the needs and potential contributions of these other parents.

> Back when our son was born, it was still common practice that the mother was put out for the birth, and the father waited in a smoke-filled room. The doctor came in and told me that our son was not "right," and explained his handicap in somewhat clinical terms. I was so shocked that I couldn't muster the energy to ask

> any questions. The pain I felt at that moment made my very heart ache with sadness. The doctor went on to remind me how strong I would have to be for my wife, as she was not yet aware of the situation. I tried very hard to comfort her, and still remember how selfish I felt that I wished I had someone to comfort me.

The fathers to whom I spoke said that they tended to remain silent or passive in situations involving their child where they normally might have been more aggressive. When I pressed them for reasons, I got the following reply from a father who seemed to speak for the majority of fathers I spoke to:

> I have never before been involved with so many professional people...the statements and advice they gave us concerning our child seemed so final and infallible. I was fearful that I would show my ignorance if I challenged them, after all, they have been to school for years, learning all about my child's disability, and we had only heard a small sampling of information over the past six months. I felt inadequate, and figured they had to know best.

Professionals do, certainly, know their various fields of expertise, but the input and information that parents, including fathers, can offer should be viewed with no less significance than the information the professional can offer the family.

Parent as Teacher

Just as a disabled child's world is limited, so too are the child's educational experiences. The day comes when the child is no longer eligible for school services and must make the transition to the adult world. If the parents and professionals have worked as a team, the parents should be somewhat prepared to teach their child the additional skills the child will need to exist in a world outside of the family's home. In his book, Albert T. Murphy (1981) describes the parents' feelings about successful relationships with their child's teachers and therapists. They expressed their feelings, and the special skills they learned, as follows:

> They included me in the activity planning right from the start.
>
> She not only did her own job but always tried to keep me informed of all the other services and agencies we'd be needing. She'd go out of her way - was really concerned.

> She helped me to feel better about my son and about myself without kidding anybody - I mean, she helped us see the limits too. She helped me to get beyond "whose fault" to "nobody's fault."
>
> I learned that I could really do something, not just hope and wait for others to act (p.149).

The positive experiences with professionals these parents report set the stage for preparing parents to assume certain unique teaching responsibilities, teaching their child life skills that the child learns at home and will later generalize in other settings.

There are a variety of skills and values that are most appropriately taught by the family. Sondra Diamond (1981) has outlined five of these skills:
acceptance of the disability; decision making; freedom of choice; risk taking; and a sense of privacy. The first is the ability to accept a disability. Parents begin to teach their child this acceptance as soon as the child realizes that he or she is different--for some children this may be when they are as young as three years of age. The parent must then begin to teach the child how to live with a handicap in a world of

non-handicapped people. The child continues to learn this acceptance for the rest of the child's life. In order to help their child cope with his or her differentness, parents need to make the child feel a sense of worthiness. A child who feels loved and accepted by those around him will find it easier to accept his handicap because he will not feel that it separates him from those he cares for and who care for him.

The child also needs to learn decision making skills. These skills are fostered by the child's exposure to a variety of social situations. At home, the child learns to make decisions by being given choices: What should you wear today--your red sweater or your blue sweater? What do you want for dinner--hamburgers or hot dogs? There are endless choices even a young child can be asked to help make, and as a result, the child learns to use whatever information is available to make a choice. As the child gets older, the decisions become more complex, but hopefully, the child will have learned enough to know what to base his decisions on. These decisions include how to protect oneself, whether to play in the street or in the yard, and whether to talk to strangers. We somehow take for granted that we must teach our nonhandicapped children these basic decision making skills, yet it is important to remember that it is vital that our handicapped children learn these skills as well.

Related to learning how to make decisions is learning how to exercise freedom of choice. When a child learns his limitations, he sometimes is made to feel that there remain no choices to be made. A child who is mentally retarded will not be president, and a child in a wheelchair cannot choose to be a professional boxer. We as parents must teach our children all the things they can do, so that when the time comes, they can make appropriate choices for themselves. This begins when we as parents learn to respect the choices they do make. For example, if a child does not want to attend a therapy session, we can try to convince the child why he or she should go, but rather than force the child, we must respect the child's final choice. The child who knows he or she is not trapped into the sessions may find future participation a little easier to realize.

In the process of learning and developing their potential, children will need to take risks. The child who falls while learning to walk learns what mistakes not to make. Learning comes from experiencing failure and disappointment as well as success, and risk-taking is required in all new endeavors. The benefits of taking risks are learning how to succeed and perform new skills; if a child knows emotionally and physically what the pitfalls are, he'll have learned how to avoid them, and in the process learned a little about personal survival.

A handicapped person's privacy is somehow always being invaded. People feel free to stare at the child in public, and to touch or move the child without waiting for the child's approval. This can lead to a distorted self image. Parents must help the child learn that the child is entitled to the privacy of his or her own personal space. The handicapped child must also, in turn, respect others' personal space and need for privacy.

Each family will have their own ways of teaching their child these life skills and values. But these are skills that are most effectively taught in the context of the child's home and community. The child will gain from these skills whatever effort the family puts into teaching them. This is more easily accomplished when the skill the parent is teaching is one that the parent feels comfortable with. Growing up with a disabled child should be a joy and is often a struggle, but it hopefully remains a learning and rewarding experience for parents and child.

Future Concerns

I have yet to speak to any parent of a handicapped child who does not, in some shape or form, dread the future. In the very early stages of our lives with a handicapped child, we are taught discipline--we force ourselves to live in the present.

If you are a parent, you can imagine just how very difficult this can be. Before a child is even born, we pick out a variety of names and imagine the personality the named child will have, and the possible future the child will have. Every mother, for at least a fleeting moment, imagines that her son or daughter might someday be president, or have a career of some grandeur. We imagine and we project our fondest wishes and dreams on a child we have yet to meet. When that child is born handicapped, those joys and dreams go instantly up in smoke. We don't yet know the child's potential or degree of impairment--we only have the name of a syndrome, or anomaly, or illness to go on. We have, too, professionals' guarded and generalized statements: "These children usually..." or "Our studies have found that most children..." These are shaky statements on which to build our child's future. We, from the very beginning, often know all of the futures our children will never have--they will never be doctors, lawyers, presidents, business tycoons, or professors. And the list goes on. It is etched painfully in the heart of every parent with a young handicapped child. We are left only with the question of what can our child do? What career can we hope for them? Will they ever live on their own and earn a living? Can they ever marry and have their own family? These questions can only be answered as we watch our children grow, and as we observe what special talents they have. So, in order to survive, we are forced to live one day at a time, and not plan too far into the future. We guard ourselves against the fear that the original pain of the initial diagnosis will creep up and catch us unaware, and in a small way, we lose a little bit of the control we try to bring to our lives. When this happens, the familiar feelings of despair and fear haunt us once again, only, as time goes on, we have resources to draw on to bring our lives back in sync, getting ourselves back on track, and taking one day at a time.

My son is still only a toddler, and right now I find it difficult to even think of visiting group homes and checking out what kind of life he'll have in them. I have just enough strength inside to contemplate his move from his early intervention program into the public school system. And even that transition raises fears about what the future will bring.

Of all the families I have talked to, not one said they felt they had the future settled as far as their handicapped child was concerned. These children ranged in age from infants to adults 26 years of age. This mother expresses the uncertainty that even parents of an adult-aged handicapped child face.

> My daughter finally got her own apartment and could take care of her finances. Paying her rent, balancing her checkbook. She has Down's syndrome (age 26) and

> has been taught a variety of skills, but she had no interest in getting a job. I didn't want to push her, but prayed that she would find something to do with all her free time. I was so worried, and only annoyed her with my fears. Finally she joined a church, and now is so busy with the church activities--the sewing club, the garden club, cooking for functions--that she's never home!! I went to bed thanking the good Lord for allowing me some peace of mind in my life!

Parents also worry about one or both of them dying and leaving the child's care up to the surviving parent, or worse yet, leaving the child alone. In the back of every parent's mind is the hope that he or she will outlive the handicapped child. In order to reduce that fear of the unknown, we as parents must learn to begin planning for the future needs of our young special child, and to begin to establish expectations for our child's future. The best skill I believe we can teach our children, that will enable them to have the very best future possible, is to learn to love themselves, to learn self-esteem and to cherish it dearly. We begin to teach our children this basic life skill when they are very young. We must make them feel a sense of worthiness, and to wear it like a badge of courage, because basically, that is the most valuable skill we all possess that helps us to get the most out of our lives.

CONCLUSION: THE GROWTH OF TRUST

As a parent of a handicapped child, you are extremely vulnerable. You must accept that yours will never be a typical family, and that you will always be thought of as different from most families. You will almost always interpret a smile from a passerby as one of pity and then, perhaps, of friendliness; your emotional guard is always up. In light of this heightened sensitivity and resulting vulnerability, it is no wonder that we parents develop close bonds to the professionals who work with our handicapped children. First of all, they are so knowledgeable, and in this knowledge, the source of hope for our children. Second, they are so accepting of our children. We can relax in their presence, they are safe people, while contacts with others outside the immediate family circle are often uncomfortable and occasions for anxiety or embarrassment.

> I found myself dreading taking him to the supermarket. I didn't know if people smiled at my child because he's cute, or because they knew he's retarded, and they felt sorry for me...

I feel that we as a family of a handicapped child need more than anything else the security these professionals offer us.

We need to believe, to trust in these professionals when they tell us that their physical therapy will enable a child to walk more like a "normal" person, and therefore be more readily accepted in society. That certain speech therapy will enable our child to master our language, and in turn, make it easier to communicate with others. That certain work programs will prepare our child for a job that will provide an income, self-esteem, and will relieve our family and society of the financial burden of caring for him throughout his or her adult life. Most of all, we need to firmly believe that our child will grow to be loved just as he loves, and to be accepted as a worthwhile human being. Finally, we need to believe that all the studies, interviews, and pounds of paper we volunteer to complete for their research will result in a richer and more rewarding life for our child and others like him. I as a mother, my husband as a father, and my two other children as his brothers, all depend on the knowledge of every professional we come in contact with. We look to them to give us something more we can believe in that will give our less-than-perfect child a more perfect life. It is no small wonder, in light of these expectations that we hold each and every professional in an emotinonal light... after all we are placing our hearts into their hands.

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